Over the past few months Raphy Rosen has been sending us updates from his job as the CSSR-TCC intern at the Terence Cardinal Cooke Health Care Center. He’s walked us through stories of former beauty queens, dabblers in polytheism, lovebirds, and resident cheerleaders, to name a few. While these stories are moving and more often than not, highly entertaining (thanks to Raphy’s dry wit), they are each written from the perspective of the observer. In his final post, Raphy shifts his view and attempts to portray life at TCC through the eyes of an admired patient. With this post he comes full circle from his position as a new intern trying to get comfortable in his long white coat, to a friend and confidant to the patients with whom he works.

14- Through Their Eyes

Mr. Johannes Berliner (name changed) is in his mid-sixties, relatively young for a TCC resident. He came here due to end-stage kidney failure which forced him to live near a dialysis center. After ten years of dialysis, with innumerable complications and hospitalizations, Johannes finally got a kidney transplant which keeps him off dialysis. His immune system is quite suppressed to ensure that the kidney is not rejected by the body, so he is at high risk for infection. According to Johannes, he has been twice told by surgeons that he will probably not make it off the operating and table, and twice he has beaten the odds. Johannes Berliner is my favorite resident in TCC.

Johannes is extremely intellectual. He pursued a PHD in biological ecology for a number of years, but was unable to finish since he dropped out of school to care for his ailing parents who died within a short span of each other. After that, he worked for the US Energy commission until he became institutionalized for his renal failure. Johannes spends most of his time in the multimedia room researching obscure inventions and breakthroughs in the scientific community, which he wishes desperately he could rejoin. He knows much more about history, politics and science than I do (not a particularly difficult feat) and is quite sarcastic and acerbically witty. While I admire Johannes’ intellect and curiosity, what impressed me about him is his character.
As happens with a surprising number of residents in TCC, Mr. Berliner struck up a romance with Ms. Rosa Marino, a resident on the Huntington’s unit. Rosa has two daughters from a previous marriage, who were aged 10 and 12 when Rosa was institutionalized. While Rosa was still in good health, she and Johannes did everything together and were known throughout the building as the TCC lovebirds. Johannes admits that their relationship was a strange one for a number of reasons, among them that he is Jewish and she is an Italian Catholic. When I asked Johannes if he had considered formally marrying Rosa, Johannes told me about an encounter he had with Rosa’s brother, a former police officer, who had heard about their relationship: “He came up to me, looked me straight in the eye and said in a growl, ‘You know, in my family, a mixed marriage is an Italian Catholic marrying a Spanish Catholic.’ I got the message loud and clear.”

Tragically, their relationship has an expiration date on it, in the form of HD. While Johannes remained in good health and even improved, Rosa declined to the point where she was confined to a recliner and can hardly speak. Johannes still wheels her out of the HD unit to go to different recreational events (at which he usually sits on the side and makes snide remarks) or just to sit on the patio outside of TCC to watch the traffic go by. He is one of the few people who can evoke a response from Rosa now. They still tease each other, but mostly Rosa sits quietly or cries that she misses her daughters, now aged 20 and 22. Rosa’s daughters used to visit very frequently but have found seeing their mother in her current state so difficult that they cannot visit as often. I think about these girls and I cannot fathom their lives and their futures. They have divorced parents, an aunt who died from HD, a mother and uncle who are dying from it, and one healthy uncle. They know in the back of their minds that they are 50-50 odds for HD and that they have not yet been tested for the HD gene. I wonder at the decisions they must make. Will they be tested before they have children? Will they just take the risk and hope that they are not carriers? Will they tell their spouses? What if both sisters have the disease? What if one does and the other does not?

Aside from Johannes’s devotion to Rosa, he displays a remarkably balanced understanding of TCC that I have not seen in anyone else, resident or staff. On the one hand, his perspective on issues that arise at TCC is very much one of a resident. He complains, like others, that the food is poor, that many staff members ignore residents and their lack of true caring is obvious. On the other hand, he acknowledges that most residents do not even make an effort to understand the mindset of a nurse or a CNA. Residents often think that he or she is the only person who needs care on a floor and fail to appreciate the enormous patient load that each nurse/aide must care for and the stressful nature of their job (changing diapers, bathing residents, cleaning festering wounds, etc). For this reason, Johannes tries to be cheerful and appreciative to every staff member at TCC.
I sat with Mr. Berliner in the auditorium and talked for a full hour and I tried to see the world out of his eyes. He said “hello” and “good evening” to staff members walking in and out of TCC. We sat as the day shift left and the evening shift came on duty. He greeted security guards, therapists, administrators and other patients. It occurred to me that the there is a great deal of meaning to the word “resident”. He truly resides there. He has no other home to go back to after an 8-hour shift or on a vacation day or sick day. Under his watchful eye for the past 12 years, staff have been hired and fired, residents have been discharged, transferred and buried and students like me have come and gone leaving no trace but manila files gathering dust in the director’s office. To the residents, we are really transient presences in their lives that are fixed and immobile. I think that an appreciation of that fact, that TCC is the one and only home for most of its residents, would contribute to a much more sensitive quality of care from the staff.
Raphy’s last account chronicled the bright side of living at TCC; the camaraderie and playfulness that at times exudes from the patients. This sunny reality is made much more exciting by the contrasting darkness of that to which it is opposed. While hospitals strive to cultivate health, they are inevitably overshadowed by illness and loss. In the limbo state that rests between serious illness and death presides a moment to make decisions, be it by doctors or loved ones. This is a difficult moment because it asks one to qualify the physical and spiritual state of a patient’s life. Raphy experienced many moments like these at TCC and has written a moving introduction and three case studies that deal with the choice between life and death.

13- A Grim Theoretical

There is no question that, in medicine, death is the enemy. Death is to be forestalled, obstructed, denied, battled and repelled at all costs. However, unlike a human adversary, defeat by the hands of this foe is certain. No one, not Teddy Ballgame, not Dolly the Sheep, not Juan Ponce de León[1], nobody has ever escaped death. In that sense, we are all really palliative patients from the moment we are born until the moment we die. The question that baffles society today is: when does better quality of life outweigh the value of prolonged life?

For the vast majority of medicine, this question is irrelevant. Let’s imagine for a moment that I go to visit my doctor for a cold that I develop during my days of Columbia-induced sleep deprivation. The doctor is not going to sit down, face me at eye level, and say in hushed, serious tones, “Raphy, let’s talk about your goals for this type of care.” There is obviously nothing to talk about. I just want to take some medicine, sleep a little, eat my mom’s chicken soup, and recover so that I can continue being the brilliant, attractive, humble person you see before you today.

Let’s change the scenario.[2] Instead, I want to buy some absurdly overpriced cereal, so I walk across Broadway to Morton Williams. On the way, I am hit by a taxi barreling along at three times the speed of sound. I am in a coma caused by bleeding in the brain. The doctor wants to operate to relieve the pressure in the hopes that I will eventually retain some cognitive functioning, though it is clear to anyone who is remotely honest that I will never be the same. I will probably never learn a page of Talmud again and I will certainly not be going to graduate school. But I will probably walk, smile, eat and, with effort, speak.
Is it worth it? Most certainly. To me, it is worthwhile to endure the pain of the operation and recovery in order to gain an indefinite number of years of a happy, simple life.

Surely you can see where I am going with this.

What happens after 5 more years when I develop blindness and weakness secondary to the brain damage? You have a bed-ridden 26-year old Raphy who cannot read but can still listen to the radio and talk to family. This Raphy develops a huge pneumonia due to a severe Boston winter. Do you shoot him full of antibiotics and hope he bounces back? I think yes, but I am less sure.

Six months later, Raphy has lost what remained of his leaky memory. He has no clue who his friends are when they visit. He recognizes the voice of family members but does not really talk anymore. He now must have regular operations to remove fluid from his brain. These procedures leave him in visible pain, from which he has no respite. Eventually, the doctor prescribes methadone which removes the pain but leaves him basically unresponsive. He can still swallow food but that is about all he can do. The doctor wants to know whether he should continue draining the fluid from Raphy's brain. What are the medical benefits and what are the risks? What are your goals for this type of care? Obviously, if the fluid is not drained, the bleeding will eventually crush his brain and his breathing will stop. On the other hand, the expenses of the operations are immense and cause much discomfort. What now?

Obviously, this case was contrived by me and I actually have no idea if it makes even the vaguest medical sense, since that is not the point of the story. The point of the story is to avoid Morton Williams.

Just kidding. The point of the story is that, at a certain point, one must ask what the goals of care are, especially when the value of prolonging life seems dubious at best and downright torture at worst.

There is no point in you listening to morbid cases invented by me, when I can tell you 3 true stories that will make my point much more effectively. Each case demonstrates a different balance between aggressive life-extending care and palliative comfort care. While I obviously have my own biases as to how well each case was handled, I will try to present them in an objective way so that you can render your own judgment. Names are changed, as always, to protect privacy.
The first case is that of Enrique Valdez. Enrique had lived with advanced dementia for many years now and had been cared for by his diligent wife, Raquel. They lived in their apartment in Manhattan until Enrique developed a urinary tract infection that left him immobilized, vomiting and agitated. He went to a hospital ICU where the infection was treated and his condition stabilized. One ICU doctor sat down with the family and explained the principles of palliative care; that the goal was not to hasten death but to allow a person to live out his or her life in the maximum possible comfort. The family was quite taken with this style of care and decided that they wanted a facility in which Enrique could receive palliative care. The family heard about TCC’s impressive palliative program and Enrique became a patient.

The family immediately made very clear that they wanted comfort measures only for Enrique. Raquel, Enrique’s health care proxy, put in place the advanced directives “Do Not Resuscitate”, “Do Not Intubate”, “Do Not Hospitalize”, “Do Not Give Artifical Nutrition/Hydration” at once. During his first month at TCC, his ADLs (Activities of Daily Living) declined. One morning, when Raquel was trying to feed him, Enrique vomited copiously. It is unclear what happened next. The wife and the doctor each claim that the other one panicked and demanded that Enrique be sent to the hospital, despite his Do Not Hospitalize order. In the end, Enrique was transferred to Mount Sinai Hospital against his recorded directives. He and Raquel sat all day in the hospital but there was nothing that they could do for him so they sent him back to TCC. Enrique’s daughter Angela arrived the next day from Atlanta. She and Raquel were livid that the facility disobeyed their explicit advanced directive and that they sat pointlessly in the hospital only to be sent back.

Enrique was placed on the TCC End-Of-Life protocol, which entails specialized pain management, extra social services and pastoral care visitation, conversation about Advanced Directives, bereavement and coping. Angela and Raquel sat in TCC most of every day to say goodbyes to Enrique. They played him his favorite classical music and read to him from books he enjoyed. All of the evidence suggested that Mr. Valdez would die imminently.

Yet, Mr. Valdez did not die, not right then at least. He continued to eat and to drink and his condition stabilized again. His family was somewhat at a loss for how to take this. They had taken the time out of their schedule to come be with dad at the end of his life and now it was not clear that death was immediately in the cards. In the end, they decided to stop feeding Enrique orally. He may have been an aspiration risk and so to avoid developing pneumonia they stopped feeding him entirely. I stood by his bedside as he pleaded in his
raspy voice for water and Raquel looked sadly at Angela who said “Mom, you know he is not supposed to be drinking”. They gave him enough water to wet his mouth and keep him comfortable, but not more. He received regular doses of extra strength Tylenol and Morphine as needed to ease his agitation. After about five days of no food and little hydration, Enrique died.

Mr. Phillip Siegel is a blind geriatric patient with metastatic colon cancer. His prognosis is quite grim, but he has yet to succumb to the disease. Every few months his blood hemoglobin falls precipitously due to bleeding in the stool and his cognition declines with it. His wife, Ellen is his health care proxy though she refuses to make decisions for her husband and instead delegates them to her daughter, Marissa. Marissa insisted that her father continue to receive blood transfusions at the hospital. When the phlebotomist tried to draw bloods to see Mr. Siegel’s hemoglobin levels he flatly refused to let them. Every time they wanted to check his levels or transfuse him, the staff had to call Ellen or Marissa and put them on the phone as they cajoled Phillip into letting them continue the procedure.

I sat in on a floor meeting in which the staff tried to convince the Siegel family that it is medically futile and, in fact, immoral to continue to force Phillip to be transfused since it is clearly very painful for him and he has stated quite plainly that he does not want these interventions. They pointed out that they could alleviate any pain and he would be comfortable and cognizant until the end. He would be able to die in his bed at TCC surrounded by staff he knows and who care about him. As the nurses and social workers made their case, it was obvious that Ellen was wavering and was unsure of what she wanted. But Marissa was adamant. She berated the staff for what she said amounted to physician-assisted suicide. Sure, she knows that her father was going to die in the near future, but to allow him to simply die from lack of blood oxygen was tantamount to murder. She insisted that her father was not in his correct state of mind and that his refusals to allow transfusion were simply because he could not understand the severity of his condition.

In the end, they reached a compromise. Since Marissa was the one who was most insistent that her father be transfused, she would come in every week to coerce her father in person to allow them to draw bloods. The nurses were sure that after a few weeks Marissa would realize that her father truly did not want this aggressive care and would have been much happier being left to die in peace. But Marissa did not give up. She has come in every week since early July and Mr. Siegel is still living against his will.

Ms. Sylvia Lorraine came to the Huntington’s Disease ward of TCC in 1992. Sylvia was 24 when she arrived and is to date the youngest person ever to be admitted to the HD unit.
When she was younger she was a child model and was prom queen in her high school class. As I write this post I am staring at old pictures from her early days at TCC that the recreational therapist showed me. She had short brown hair, pink lipstick and a classic girly pout on her face. She was indeed quite beautiful. She spent more than 15 years on the HD unit, getting progressively worse as the disease took its inexorable course. She eventually became wheelchair-bound and her arms and face grew contorted and twisted. In the past year she developed breathing and swallowing difficulty and was transferred to a unit that specializes in tracheotomies. She had a gastric tube inserted because her chorea made her an aspiration risk while swallowing food.

Sylvia was stable in this condition for about a year before one day in late July her condition worsened dramatically. Her gastric tube became dislodged and the surrounding area began to hemorrhage. Her breathing became rapid and shallow and she was in obvious pain. I was about to leave work for the day when the director called me and said “Raphy, you can’t leave yet, we need to go see Ms. Lorraine.” I do not know what medical intuition guided him, but our timing was perfect. Just as we walk into her room, we were followed in by her foster mother and brother who had just arrived. Her mother was coincidently in the area for a family gathering and had rushed to TCC when she heard that Sylvia was deteriorating. Sylvia’s family was clearly devastated but seemed fairly composed since they knew for many years that this day was bound to come. Sylvia had a Do Not Hospitalize order in place and the family intended to abide by it. They kept saying how sweet and beautiful Sylvia used to be and that we cannot understand since we did not know her in her youth. The director called the evening staff together and told them that this would probably be Sylvia’s last night on this earth. They were all extremely solicitous to the family and offered them dinner and a place to sleep if they wanted to stay the night.

The next day in morning meeting one of the nurses announced that Ms. Sylvia Lorraine had died in her bed at midnight. The reverend and the rabbi had both gone to see her and pray and reported that she was quite peaceful and even smiled faintly at their touch. The nurses and aides on the HD unit that had cared tirelessly for Sylvia for so many years had a chance to pay their final respects. Many attended her funeral the next day.

Each of these cases depicts a family giving a different style of care to their loved one. How can I judge their decisions having never stood in their shoes? To me, it seemed that the Valdez family may have accelerated their father toward his demise prematurely while the Siegels represent the opposite extreme of intense devotion to the point that they are forcing a life of torment on their loved one. I do feel that I understand a decision like the Siegels, however. When I look at Phillip Siegel, I see a shadow of a man. He looks emaciated, wasted and tired. This is the only Phillip Siegel I have ever seen and the only
one that any staff member at TCC has encountered. Yet, when his wife or daughter looks at him, they see his former self. They remember a vibrant young man full of life and optimism. It is this memory that they are clinging to more than his current condition. I think that bridging this gap, appreciating the wonderful past while acknowledging the tragic present is essential in resolving conflicts around the end of life.
Playful Times at TCC
by Raphy Rosen
August 17, 2010

Some children remark that as they grow older, the roles they play with their parents seem to switch. The cared for become the caregiver and vice versa. This seemingly cyclical reversion to a time of jovial frivolity does not escape the patients at TCC. With his ever-reliable dry wit Raphy brings us a short anecdote that likens a festive day at TCC to a sweltering, Kool-Aid filled day at summer camp. Soon to follow will be a few case studies that emphasize why these moments of care-free fun are so important, so check back soon.

12- The Light Side of Life

I want to dispel some misconceptions here:

A few people who have read my posts have told me with a measure of sympathy in their voice that they are sorry to hear that my job this summer is so difficult and depressing.

Based on my ‘cheerful’ posts about the ravages of HD, discussions about withholding treatments, the disconnect between the aides and their patients, and family-staff discord, I understand why one would get this impression. But I want to make crystal clear that these grim, gut-wrenching tales only represent a small portion of existence at TCC. I write about these subjects because they are controversial, unusual and evocative. However, one must realize that most of life at TCC proceeds pretty much like mundane normal life. Residents eat. They watch TV. They complain about food. The few technically savvy among them surf the internet. They read, they participate in music groups, most call or visit family. Some have cliques of friends like you would find in any high school. There are a few popular residents who get visitors from suitors of the opposite gender. There are romances and even marriages. There are introverts, bullies, intellectuals, jocks and whiners. And this reality is exactly the goal of a facility like TCC – to allow residents to maximize their time remaining in this world. They do this not by focusing constantly on the inexorable approach of death but by appreciating the life and vitality that still remain. Here is a small taste of the light side of life:

Last Thursday, ESPN came to TCC and threw a sports carnival in the auditorium. Their employees ran games such as shuffleboard, bingo, mock horseracing and blackjack. The residents who were able to come down competed for colorful prizes such as t-shirts, hats and mugs. The most exciting part of the event was the water fight held on the patio outside. Predictably, the water fight degenerated into 12 wheelchair-bound residents
soaking the recreational therapist. However, due to the chorea (muscle spasms) of the HD patients, most of the onlookers on the periphery were doused as well. Watching this (I held back my competitive streak that would dictate that I grab a water gun and shoot back), I was forcibly reminded of summer camp, an experience so formative in my younger years. It seems that the ‘camp environment’ of competition, play and friends can be equally central in one’s older years.
A quick note: I spoke with one of the nurse managers, Ms. Rose Smith, who has a background in palliative care and worked as a hospice nurse for many years. She made one particularly interesting point about palliative care which is well worth sharing:

Ms. Smith hates the word “expired”, which is common parlance in nursing homes to mean that someone died. Ms. Smith derided the usage of this word because, in her view, it is being used to shield the speaker from the raw reality. Instead of needing to think about the awful thought that someone you care about is dead, it is easier to pretend that they are a carton of milk that had a set expiration date that has now passed. But it is offensive to the memory of the person to refer to them as if they are something subhuman simply so we can shield ourselves from thinking about the truth. In a facility like this, where death is a constant presence, we must train ourselves to view death as a natural occurrence that is not to be feared nor is to be blamed on a particular person’s negligence. It is simply the next stage of life. And to quote Albus Dumbledore (my quote, not her’s), “Fear of the name increases fear of the thing itself.”
The Place of Religion and Doctor-Patient Relationships at TCC
by Raphy Rosen
August 2, 2010

Each week or so when Raphy sends me his next installment of posts on his time at Terence Cardinal Cooke Medical Center, I open the files, begin to read, and am immediately taken in by the candidness of his observations. Almost all of Raphy’s posts include one or more vignettes concerning the life and experiences of a patient at TCC. He is able to share with us not only the physical trials they have faced, but the emotional and spiritual experiences that have occurred in response to the patients’ toils. In these following posts on the place of religion at TCC and the trick to maintaining a reciprocal doctor-patient relationship, Raphy explains to us how he builds trusting relationships with patients at TCC and brings us the stories that he is privy to as a result of these unique relationships.

10- Religion at TCC

I want to describe the role that religion plays in a facility like TCC. Obviously, as a Catholic institution run by the Archdiocese, there are crucifixes and other votive objects hung in every room and office. I want to describe something more subtle, however, and that is a few personal stories and observations that illustrate the role that G-d plays once a resident has realized that there is not much more that man can do for him:

Jim Miller is an elderly resident who suffered a right-side stroke a few years ago. He is wheelchair bound and has only very limited use of his left hand. Jim is quite talkative and will lecture almost anyone who will listen about the grace of G-d and the miracles that he has experienced. He told me that when he was younger he was not religious at all, in fact, he spent time in prison for drug usage and dealing. Since then, Jim has searched for meaning in his life and has found it at TCC in the form of eclectic religious observance. Jim, originally a Baptist, attends Protestant, Catholic, Jewish and Muslim services. He has proudly shown me his Yarmulke numerous times and often carries with him books about religion. Smiling, Jim told me that “he would be part of any religion that worships G-d and that with a useless left hand like mine, I can use all the help I can get!” He also told me that he prays over his hand, washes it with holy water and that it he is slowly regaining sensation and control over his hand. On a rational level, I am rather skeptical of his rosy self-prognosis, but on an emotional level, I am deeply impressed with Jim. He has changed what sounds like a crime-filled past into a present of religious reflection and study.

In addition to religious revivals later in life, it is fascinating to see what elements of one’s religious life that people remember. Max Simon is a blind middle aged Jewish resident with HIV/AIDS. While he was not an observant Jew during his younger years, he is very
impassioned about the Shabbat services run by the facility rabbi. When he arrives for services, he can barely contain his cantorial voice and regularly interrupts services with the soulful liturgical song *Adon Olam* that he remembers from his youth. I suspect that this does not stem strictly from religious fervor like Jim Miller's but instead from the exquisite pleasure of remembering one's hallowed youth. Max is equally enthralled to tell us about his hairdressing career or his favorite deli on the Upper West Side as he is to engage in prayer service. Since Max has AIDS-related blindness, he recites the prayer from memory. His memory of this song represents a link to his brighter past, one that he has precious few reminders of. I wonder when I am older and my memory begins to fade (moreso than it has already, if possible) what elements of my current life will stick with me through whatever decline my body undergoes. I doubt that Max's Jewish schoolteacher from the 1950s appreciated that the song that he was teaching him would be his strongest link to his religion and his past.

“Advice on Talking to Patients” after the jump.

11- Advice on Talking to Patients

As much as I would like to think that my enjoyment here has been due to a natural propensity to interpersonal contact, especially with the geriatric community, the truth is that I have had some useful advice along the way.

A few weeks before I started work here, I met, Rabbi Alan Shif (name changed), an aged rabbi who had worked for many years as a chaplain at a large prison in New York. Among other things we talked about, I told him that I would be working at TCC and that I would undoubtedly get first hand exposure to the types of work that chaplains do. He gave me a few pieces of excellent advice before coming here that have guided my interactions with the residents.

First, he said that if a resident offers you anything, be it a hat, food, drink, etc, you must accept it regardless of if you are cold or hungry. He explained that when a resident proffers you something, he/she is trying to forge a relationship of equals. In a facility like TCC, the visitor is almost always more able-bodied than the resident. For that reason, in an effort to be kind, the visitor will often rearrange the resident’s pillows, hand them something out of reach or other such minor favors. Even the act of visitation itself— taking time out of one's day to sit and chat with a resident is clearly a one-sided act of charity done to the patient. Rabbi Shif explained that a resident wants to feel like they are reciprocating in some way by giving the visitor a token of some sort, whether the visitor wants it or not. By accepting and enjoying the gift, the visitor does the truest act of kindness— making the patient feel...
empowered and helpful. I applied this particular gem of wisdom when visiting Tatiana Chechelnitski, a Hungarian geriatric patient. Tatiana keeps a store of bananas in her room and offers them to her visitors. I made sure to accept the banana and eat it in front of Tatiana so that she could derive the grandmotherly satisfaction of watching a young boy eat and so that she would feel that she has done something for me, personally, as well.

In my conversation with Rabbi Shif I added that one of the areas I would be studying is the area of advanced directives and End of Life care. He cautioned me to remember that when visiting a patient, I must allow them to direct the flow of the conversation. Some people want nothing more than to vent about their condition. They show me their wounds, feeding tubes, discolorations and lacerations at the drop of a hat. Others love talking about their families (be careful with these or they will show you more pictures than you imagine possible to fit in a wallet). Other patients want nothing more than to make small talk about Puerto Rico or Obama or the inhumanly hot summer. The point Rabbi Shif was making is that even if I have grand ideas of discussing hugely consequential moral, emotional and spiritual issues with a patient and contributing to a patient's acceptance of their inexorable demise, I must not impose my agenda on a resident. It is possible that after we have created a relationship regarding other matters, a resident will feel sufficiently comfortable with me to discuss important life (and death) issues. Others may just not want to talk about it, and that is ok too.

I have tried to let his advice guide my interactions with patients so that my chats with them are for their benefit as well as my own.
It is easy to take the relationship between body and mind for granted. We wake up in the morning, kick the alarm clock across the room, and pull the sheets back over our heads with little thought. There are few people who would simultaneously consider the neural activity that precipitated their habitual movements while burrowing farther under the covers for those last fleeting minutes of rest. This easily forgotten relationship is at the center of Huntington’s disease, one of the most physically and emotionally devastating genetic disorders. Terence Cardinal Cooke Medical Center has a well-reputed program for HD patients ranging from 20 to 70 years old with need for special care. Raphy Rosen, a CSSR-TCC intern, recently spent time in the Huntington’s disease unit of TCC speaking with patients and their loved ones. Here he brings us powerful stories of the battle between an unsympathetic disease and the people living with it.

9- Huntington’s Disease

The single most inspiring experience that I have had at TCC was on June 14th when TCC ran a Huntington’s Disease orientation for NYMC students. TCC is renowned for its unique care for HD patients, and it has one of the biggest HD units in the country. For those who are unfamiliar with HD, it is an autosomal dominant genetic disorder that usually shows symptoms in a patient’s late 30s-40s. It is a disease of the Central Nervous System and interferes with a person’s gait, speech and in its later stages, cognitive functioning and swallowing. As the medical director described, it results in a person with a fairly intact mind being trapped inside a completely non-responsive body. Patients will often develop Chorea, which means that the muscles begin to jerk uncontrollably to the point that they are completely unable to care for themselves or perform even the most basic activities of daily life. In fact, HD patients burn far more calories than an unaffected individual since their muscles are in constant motion. As of now, there are drugs that can briefly mitigate some of the symptoms, but there is no cure.

The horrifying thing about HD is that it strikes right in the middle of life. As part of the orientation, Dr. Fran Brown (name changed to protect privacy), one of the newer HD patients on the floor, came to speak to the students. She had been a physician until just recently, when her muscles became too jerky and impaired to continue her practice. Since HD is a genetic disorder, she knew for a long time that she had a 50% chance of having the disease since her father was affected. She described the isolation her father experienced. People would stare at him in the elevator, the street, the office. Fran was petrified that she would experience the same thing, so she lied to everyone she knew about the disease when she began to exhibit symptoms. She told them she had seizures, strokes, psychiatric
disorders, anything so that they would not know the truth. In fact, Dr. Brown related that
during the earlier stages of the symptoms, she took to bars in order to make her small
involuntary motions appear to be the results of drinking and not her disease. In fact, she
met her current boyfriend in one of these bars, to whom she eventually told the truth. He
has stuck by her despite her deteriorating condition and visits her on the unit often. Fran
elected not to have children since she did not want to risk passing on this devastating
disease to them. Instead of having her own children, Fran chose pediatric medicine as a
way of fulfilling her love for children without having her own. Fran described how she
secretly hoped against all rationality that by practicing as a physician, she could somehow
protect herself from the onset of the disease. Fran was forced to enter an institution since
she had numerous DUls since the police assumed that her swerving car and failed straight-
line test were due to drinking. Since then, she has taken advantage of the trips and
activities available on the HD ward, but of course, her existence is a pale shadow of her
former rich life.

Perhaps the most shocking realization was the extent to which Fran was in denial about her
future prognosis. After we heard during the director's lecture that there is no known cure,
Fran described the cocktail of miracle drugs that she was receiving, and how much better
her symptoms were. She told us that she would soon be going back to live in her
apartment with her boyfriend. After she had left, the social worker told us that her hopes
are mere illusions. The drugs she receives reduce her Chorea slightly, but there is no
chance whatsoever that she would ever return to society. The staff allow her to keep up her
dreams since the ability to hope is really all she has left at this point. It is incredible that
dealing with such a disease could force an educated physician, with full knowledge of the
details of her disease, to convince herself of a fantastic vision of the future.

Believe it or not, Fran's monologue was only the second most heart-rending story of the
orientation. Later, we heard from Carl Ruiz, the husband of Laura Ruiz, who is a late-stage
HD patient. Carl can be described as nothing short of a saint. He described the story of
how he met his wife. They were friendly for many years before they were married. He knew
that her father had died of HD but she seemed unaffected, so he was hopeful she was not
a carrier. Then, less than three months after their wedding, she was diagnosed with HD.
Within a year, she was wheelchair bound. Carl described Laura's degenerating condition.
At first, she only shook slightly and needed a walker to get around. After some time,
however, her movements were so jerky that she could not shower or toilet herself. Carl
would try to clean his wife only to be struck repeatedly in the face by his wife's violent
muscle spasms. Laura would apologize, despite her obvious lack of malicious intent, and
Carl would laugh it off – “You've been waiting to do that for ages, haven't you?” he would
quip. Carl spent eight years struggling to care for her in their home. His daily routine
involved the following: getting her ready in the morning, going to work, coming home
around lunch to feed her and take her to the bathroom, going back to work, coming home around 4 to take her to the bathroom and feed her dinner, going back to work, coming home around 9, getting her ready for bed and falling into his bed emotionally and physically exhausted. Obviously, having children was out of the question for Carl. In addition, his career as an attorney was in shambles since he needed to refer out any clients that required a serious time commitment. Eventually, after losing 25 pounds due to stress and exhaustion, Laura convinced him that he needed to place her in an extended-care facility. Carl told us that he recently saw a picture of them on their honeymoon when his wife was not yet symptomatic and was shocked by it. Crying, he said that he could not even remember the days when his wife was healthy.

Now that Laura is a permanent resident at TCC, Carl visits her at least four times a week, and every time Laura’s first question for him is “When are you coming again?” The social worker informed us that she is petrified that Carl would abandon her, and, based on her family history, she has reason for concern. When Laura’s mother discovered that her father had HD, she immediately took her kids out of state and left him to fend for himself. He died alone and abandoned. Knowing this fear, Carl does everything in his power to show Laura that she will never be alone.

At this point, Laura is essentially non-verbal and can simply nod and shake her head. We were given the chance to visit with her and to see the shell of the formerly vibrant person that remained. She stared blankly at us as we tried to speak to her, and seemed to hardly understand us at all. That she was formerly a loving wife and superstar ICU nurse was tragically totally indiscernible to us.

The other fascinating discussion during the HD orientation revolved around Advanced Directives (ADs). Advanced directives are wishes that a patient has about his or her future health care that are hopefully specified while still of sound mind. For example, a person can decide while relatively intact that if they were to fall into a persistent vegetative state that they would not want artificial nutrition or resuscitation (DNR). However, the problem is that a person really has no idea what their future condition will feel like, so they are making decisions somewhat blindly in advance. A person who decides while they are mentally competent that they want to be kept alive as long as possible does not appreciate the amount of pain and disorientation they will experience after their fourth operation or their sixth round of futile chemotherapy. If the patient was able to communicate, they might make a very different decision due to their new condition, but since we only have the patient’s prediction from six months earlier, we are forced to follow what might be very out-of-date wishes. This situation demonstrates the value of a Health Care Proxy (HCP). Whether this is a friend or family member, they are able to adapt to the changes in the
patient’s condition and dictate what they think the patient would have wanted in varying circumstances. The problem with HD patients is that they often choose family members to be HCP, only to have that family member eventually be diagnosed with the same condition and be equally unable to render decisions.

While the general academic questions (symptoms, treatments, ADs, HCP etc) about HD were interesting, by far the most powerful and lasting impression that I will carry were the personal narratives provided by those who are intimately affected by the disease.

7- Huntington’s Disease

The single most inspiring experience that I have had at TCC was on June 14th—when TCC ran a Huntington’s Disease orientation for NYMC students. TCC is renowned for its unique care for HD patients, and it has one of the biggest HD units in the country. For those who are unfamiliar with HD, it is an autosomal dominant genetic disorder that usually shows symptoms in a patient’s late 30s-40s. It is a disease of the Central Nervous System and interferes with a person’s gait, speech and in its later stages, cognitive functioning and swallowing. As the medical director described, it results in a person with a fairly intact mind being trapped inside a completely non-responsive body. Patients will often develop Chorea, which means that the muscles begin to jerk uncontrollably to the point that they are completely unable to care for themselves or perform even the most basic activities of daily life. In fact, HD patients burn far more calories than an unaffected individual since their muscles are in constant motion. As of now, there are drugs that can briefly mitigate some of the symptoms, but there is no cure.

The horrifying thing about HD is that it strikes smack in the middle of life. As part of the orientation, Dr. Fran Brown (name changed to protect privacy), one of the newer HD patients on the floor, came to speak to the students. She had been a physician until just recently, when her muscles became too jerky and impaired to continue her practice. Since HD is a genetic disorder, she knew for a long time that she had a 50% chance of having the disease since her father was affected. She described the isolation her father experienced. People would stare at him in the elevator, the street, the office. Fran was petrified that she would experience the same thing, so she lied to everyone she knew about the disease when she began to exhibit symptoms. She told them she had seizures, strokes, psychiatric disorders, anything so that they would not know the truth. In fact, Dr. Brown related that during the earlier stages of the symptoms, she took to bars in order to make her small involuntary motions appear to be the results of drinking and not her disease. In fact, she met her current boyfriend in one of these bars, to whom she eventually told the truth. He has stuck by her despite her deteriorating condition and visits her on the unit often. Fran elected not to have children since she did not want to risk passing on this devastating
Believe it or not, Fran’s monologue was only the second most heart-rending story of the orientation. Later, we heard from Carl Ruiz, the husband of Laura Ruiz, who is a late-stage HD patient. Carl can be described as nothing short of a saint. He described the story of how he met his wife. They were friendly for many years before they were married. He knew that her father had died of HD but she seemed unaffected, so he was hopeful she was not a carrier. Then, less than three months after their wedding, she was diagnosed with HD. Within a year, she was wheelchair bound. Carl described Laura's degenerating condition. At first, she only shook slightly and needed a walker to get around. After some time, however, her movements were so jerky that she could not shower or toilet herself. Carl would try to clean his wife only to be struck repeatedly in the face by his wife’s violent muscle spasms. Laura would apologize, despite her obvious lack of malicious intent, and Carl would laugh it off – “You’ve been waiting to do that for ages, haven’t you?” he would quip. Carl spent eight years struggling to care for her in their home. His daily routine involved the following: getting her ready in the morning, going to work, coming home around lunch to feed her and take her to the bathroom, going back to work, coming home around 4 to take her to the bathroom and feed her dinner, going back to work, coming home around 9, getting her ready for bed and falling into his bed emotionally and physically exhausted. Obviously, having children was out of the question for Carl. In addition, his career as an attorney was in shambles since he needed to refer out any clients that required a serious time commitment. Eventually, after losing 25 pounds due to stress
and exhaustion, Laura convinced him that he needed to place her in an extended-care facility. Carl told us that he recently saw a picture of them on their honeymoon when his wife was not yet symptomatic and was shocked by it. Crying, he said that he could not even remember the days when his wife was healthy.

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While the general academic questions (symptoms, treatments, ADs, HCP etc) about HD were interesting, by far the most powerful and lasting impression that I will carry were the personal narratives provided by those who are intimately affected by the disease.
In his next posts Raphy Rosen relays stories of TCC’s one-woman cheering squad, and makes a case for the importance of input from nursing assistants in the doctor’s decisions on treatment.

7- Inspiring patients

Those of you who have been following these posts might recall a story I related earlier about a stroke patient, we’ll call her Greta, who was denied further therapy since she was not progressing after 3 months of treatment. I have seen her a few times since then and she has surprised me every time. Her method of coping with her debilitated condition has been to become the resident cheerleader on her floor. Greta would compliment the CNAs loudly to me while they were nearby and whisper to me that they receive so little recognition for their work and she was going to give it to them in any way she can. In addition, she formed a bond with Raul, a highly debilitated patient with severe dementia. Raul rocks violently back in forth in his chair and was given an extremely sturdy padded chair so he neither breaks the chair nor hurts himself with his rocking. Raul is unresponsive to speech. “Watch this!” Greta excitedly told me, and she gave Raul a “thumbs up” sign. He looked vaguely at her and continued his rocking. She muttered to herself “Oh c’mon baby, don’t fail mama now!” and gave him a thumbs up again. This time he smiled contentedly and, much to her delight, gave her a thumbs up, something I have never seen him do before or since. It seems that Greta has decided that if she cannot help herself through therapy then she is going to help everyone else instead, staff and resident alike. Rather than depression, despondency and resignation, Greta translated her frustrations into actions.

Postscript: Greta has since transferred out of TCC in the hopes that she can find a different facility that will allow her to work on therapy. I sincerely hope to run into her walking on the street in the future and telling her how impressed and inspired I am with her resilience for herself and her commitment to others.

More stories after the jump:

8- The importance of the CNAs
In order to describe the actual research project that we are working on, I need to give a little bit of background on the division of labor at TCC. On each floor, there are 2-3 nurses (R.N. or L.P.N.) who deal with the residents’ medications. A dietician regulates and monitors the residents’ eating habits and the recreational therapist keeps the residents busy and active with activities ranging from sing-alongs to bingo to trivia. However, the CNAs are the most abundant position and they also know the residents probably better than anyone else. On each floor there are 5-6 CNAs (Certified Nursing Assistants), who deal with the residents’ most basic needs such as feeding, bathing and toilet/diaper changing. The CNAs are often the lowest paid worker in the facility and experience the highest turnover rates. Many CNAs are recent immigrants who have had less educational opportunities than other workers. While some CNAs intend to spend the duration of their working life as a CNA, others view it as a temporary stepping stone to eventually train for a nursing degree.

The task to which the medical director steered us was to try to understand the mindset of a CNA who is dealing with patients that span the entire spectrum of cognitive and physical functioning. What interests us most greatly is how a CNA can manage to give friendly, cheerful, emotionally invested care to ~10 patients, especially when their work is so inglorious. In order to probe this question, we designed a two-part survey. The first section asks general questions about being a CNA like why did they choose this line of work and what things do they wish they could change about their jobs. In the second part of the survey we focused in on palliative care particularly to try to get a feel for a CNA’s role in the last months of a person’s life. We asked questions about how they feel about Advanced Directives, hospice care, difficult families and investing emotionally in patients who are unlikely to be alive in 3 months.

One suggestion that we made to the facility is to require that CNAs come to the weekly Committee Care Plan meeting (CCP), in which an interdisciplinary team composed of a nurse, social worker, dietician, therapist, and others discuss a few patient cases and modify care decisions. While officially one CNA is supposed to attend, in practice it is very rare to have a CNA present. I do understand why CNAs would not want to attend CCP. They have extremely physically demanding work and are relatively understaffed. If even one CNA is elsewhere for an hour, that increases the burden on everyone else. That being said, I think that the problems created by not having a CNA present are far more serious. The problems are two-fold, both for the residents and for the staff.

First, the message TCC sends by including the voice of every other member of the floor except the CNA is that they do not care what the most front-line caregivers have to say about their patients. CNA surveys reported a widespread complaint of CNAs is that they
are not included in the decisions about their patients, about whom they care deeply.[1] I heard about a particularly striking illustration of this that occurred about a year ago:

There was an elderly live-in dialysis patient named Evelyn Gerber, whom the entire staff adored like their own mother. Evelyn had been at TCC for 5 years and was something of a superstar celebrity among her caregivers. After some time, Evelyn’s condition began deteriorating rapidly. In a decision between the chaplain, the social worker and the family (including her Health Care Proxy), they decided to discontinue her dialysis, which meant she would die in days and not weeks. Many members of the staff were mutinous, especially the nurses and CNAs. They were disheartened that, after their meticulous and devoted care for her, her family would just “give up” and stop Evelyn’s dialysis. Obviously, this type of decision resides primarily in the hands of the patient and secondarily with the family, and that it is the staff’s responsibility to provide the best care regardless of the patient’s decisions. That being said, it would have been appropriate to at the very least explain to them the rationale behind the plan (increased comfort, patient autonomy, dignified death, etc) rather than just announcing that “Ms. Gerber will not be going for dialysis anymore” to shocked staff.

In addition to potentially offending CNAs by not including them in Care Plan meetings, one can also miss out on invaluable insights that would tangibly benefit the patient. CNAs often have greater perspective into a patient’s ever-evolving condition because they spend more time than anyone else with the patient.

Consider the following example: I have attended a few HD Care Plan meetings and, unlike most other floors, they often have a CNA present. At one particular meeting, the discussion turned to Mr. Edward Wheeler, a mid-40s patient who has the curious practice of only emerging from his room for meals and then returning to his room, putting a towel over his head and lying awake and motionless on his bed. At first glance, Edward’s lethargic routine sounds like he is suffering from depression. A few of the staff members suggested ordering a Psychology consult to determine if he would need to be on anti-depression medication. The CNA strongly disagreed and said that if you just go in to his room and talk to him, you would realize that Mr. Wheeler is in excellent spirits. In addition, his family had told the CNA that this was just one of Edward’s idiosyncrasies, and had been like that for a number of years. If this CNA had not been present, a psych consult would certainly have been ordered and Edward might have even been started on unnecessary medication. If TCC begins to include CNAs more regularly in care decisions, I think the level of care will increase dramatically.
In his time at the Terence Cardinal Cooke Health Care Center our intrepid intern, Raphy Rosen, has learned of the intricacies of staff-patient relationships. In his next two posts, Raphy discusses the complications of closeness and asks the deceptively simple question, who cares about care?

5- Not too Attached

One of the dilemmas that a facility like TCC faces is how to facilitate the best possible relationship between a C.N.A. (Certified Nursing Assistant) and a patient. On an average floor there are 50 residents and a maximum of 6 CNAs, meaning that each aide cares for at minimum an average of 10 patients. Each floor decides on its own how they divide their patients among the CNAs. For example, on the Huntington’s floor, each aide works only with their group of patients and there is no switching. This is done because Huntington’s patients are often distressed by change, and giving them a permanent aide lends some degree of stability to their lives. The disadvantages with this setup are twofold:

1) An aide is fairly ignorant about the other 40 patients on that floor, and if a crisis arises in the absence of a patient’s specific aide, they are not well equipped to deal with it.

2) Each aide is deeply connected to his or her patients and may become overly emotional concerning their care. One of the necessary responsibilities of the job of a CNA is to remain somewhat objective and removed, which is in the best interest of the patient and also in the best interest of the aide, so that the aide is not devastated at the passing of a resident.

On one of the nursing home floors, each CNA is assigned 10 patients for one month and then switches to another 10 for the next month and so on. While solving the above problems, this detachment is not lost on the residents. Consider the following story:

Sophia, the recreational therapist on floor 7, was playing a current-events trivia game with the residents. One of the topics that was discussed was Obama’s appointment of Elana Kagan to the Supreme Court. This led to a full-blown argument about the wisdom of lifetime appointments for justices. One of the objections that was raised was that if a person is on the bench for too long, they become entrenched in their beliefs and unable to assimilate new perspectives and realities. Lauren, one of the feistier elderly residents,
quipped: “Yeah, it is like you guys [referring to the aides]. You switch around who you take care of so that you don’t become too attached to any of us!” The whole room laughed heartily at this comparison, but the uncomfortable truth of this statement was not lost on anyone who was paying attention. The CNAs switch around their assignments so they do not become overly invested in their residents, as a logical defense mechanism. As necessary as this may be, the residents were acutely aware of this strategy and its implications about their confidence in the resident’s survival.

More after the jump:

6- Respect and Care

I want to describe the kind of people who work in this extraordinary institution and please forgive me for waxing poetic. The uniqueness expresses itself in two ways:

Respect:

I have never heard a patient or staff member referred to by anything other than Mr/Ms X. This instills a level of professionalism among the staff by conferring dignity to patients who have had much of their dignity compromised. Imagine you are caring for Filipe. You arrive at 11pm for your 8-hour shift which includes changing Filipe’s fecal bag, stripping off his badly soiled sheets, cleaning off spilled rice and gravy from his gown and listening to Filipe conversing incoherently with thin air. Would you be able to treat him with respect? I doubt I could. This one unofficial but effective measure, calling Filipe “Mr. Gonzalez” instead, reminds staff that Filipe was not always in this pathetic dependent state, and deserves courtesy like any other human being would. Another formality that TCC utilizes is that they will never define a patient by their disease, rather they separate the disease and the human underneath. For example, no one will refer to a “demented resident”, instead they will call him a “resident with dementia”. These conventions are subtle but are extremely valuable in instilling a place with an undercurrent of respect.

In addition, even the patients who prove frustrating and difficult are given the maximum feeling of autonomy. One case arose in which Michael was picking fights with his roommate Julio. It was clear that Michael would need to be moved to a different room, and possibly to a different floor. However, the staff did not just move Michael without first asking his permission, giving him a choice of options of other rooms, and cajoling him to agreement. The staff devoted their precious time to making Michael feel that, despite his extremely belligerent behavior, his opinion mattered and he was able to take an active role in deciding his placement.
Care:

I regularly attend the morning meeting in which the care teams discuss interesting or problematic patients and brainstorm for solutions. What is fascinating about these meetings is that they are rarely medical in nature. More often, they are discussions about which patients hate their roommates and need to be moved, or patients who report ‘stolen’ (read: lost) items, or which air conditioners are broken, or which patients can’t sleep at night since other people are too loud. It is almost comical to hear internists, psychologists, nurse practitioners, and upper echelon administrators discuss issues so mundane that every camp counselor has encountered them. The reason that these issues are given significant time is that the entire staff care deeply about their patients’ quality of life, as distinct from their quantity of life.

I also attended an orientation of new staff members in which we were taught the horribly boring intricacies of TCC bureaucracy. The meeting was mostly uninteresting except for one point which sparked much protest from the audience. The instructor said that it is forbidden for nursing staff to give patients money or treats, even if they claim to be hungry. This seems extremely logical to me- the patients are given three meals a day, as well as snacks and drinks, why would they need anything else? In addition, giving treats to one resident will cause jealousy among the rest and dependency on the treat.

However, for some reason, the staff argued vehemently. They said that it is part of the way that they bond with residents, and that it gives the residents a reward for being particularly well behaved. One R.N. put it best “Due to the nature of our job, you can’t take our humanity away from us!” a bit of an overreaction, but impressive nonetheless. In his mind, preventing staff from giving residents special treatment turns them into emotionless automatons. Even though the negatives of special treatments outweigh the benefits, I was quite surprised and impressed with the degree to which new caregivers valued the relationship that they would be building with their patients.
In his next installation of posts from Terence Cardinal Cooke Hospital and Medical Center, CSSR's intern Raphy Rosen discusses the transformative power of a jacket, the difference between the physical and the spiritual questions we ask at the end of a life, and the opposing forces of family and medical culture.

2- Physician Demeanor

I observed firsthand the power of demeanor in a hospital. The medical director at this facility has a nearly magical way with his patients. He knows almost every person out of the 730 in the facility by first and last name. As the self-proclaimed “quarterback of joy”, he runs (literally) throughout the hospital encouraging patients and staff alike to continue to hope for recovery and discharge even if there is no hope to be had. He never stands next to patient’s bedside and interrogates him or her in a distant or “doctorial” way. Instead, he gently pulls up a chair, places his hand on the patient’s shoulder, stares into the patient’s fearful, forlorn eyes and has a quiet, intimate conversation. More like an old friend than a physician, he evokes a smile from everyone he talks to, even if they don’t speak a lick of English.

As effective as the director is, there is one barrier that he cannot as a physician overcome. Consider the following story:

I was given a white coat on loan in order to appear more professional during my interactions with residents. Naturally, I had proudly clipped my “Student” I.D. badge to it and walked around the facility with a slight air of self-importance. Now I felt like I fit in, like I was going to accomplish something meaningful with my research. Towards this end, I attended a religious service to appreciate the effects of religious inspiration on End Of Life patients. After some time in the sweltering chapel, I removed my coat. The patient sitting next to me looked over at me, now bereft of badge and physician’s attire and said wryly “Aha! Now you look human.” In so few words, he had noted the all-to-visible barrier that exists between doctor and patient; one is the researcher and the other the subject, one active and the other utterly helpless. By doing an action as simple as removing the coat I had crossed the line from being a distant figure to a real person, one who could talk with a resident as an equal, as a fellow human. While a professional physician does not have this luxury, I am lucky that I can seamlessly slip between employee and visitor and use that to build a different type of relationship with a patient.
Two more posts after the jump:

3- Objectifying Death

Obviously, for the individual members of a family, a death in the family is a traumatizing experience that is unlike any other. One of the necessary measures in palliative (End of Life) care is to streamline and objectify what would normally be an emotionally unique experience. Since a facility like Terence Cardinal Cooke has seen so many critically ill patients, they must create categories and classifications to describe the precise state of each of these patients. One of the forms that the hospital places in a patient’s chart describes the various steps that they will take to care for a dying patient. Among these measures are “Assist with spiritual support. Pastoral care visits. Offer religious items i.e. □ bible, □ rosary, □ reading material.” Another line reads “Monitor for signs and symptoms of pain/discomfort i.e. □ facial grimacing, □ moaning, etc.” Undoubtedly, these are all reasonable measures for staff to take in order to care for a dying person.

However, this list may serve a dual purpose. In addition to being a reminder for staff so that all areas of a dying patient’s life are well monitored, the list also externalizes and formalizes the experience of caring for a dying person. Instead of an aide walking into a patient’s room and being hit with the full brunt of the tragedy and trauma of this individual’s demise, the aide walks in with a professional checklist of things to observe and record. The aide has formal categories by which to classify the dying. One can imagine reading one of these notes:

“Patient was verbally expressive of severe pain, and reported intense emotional distress. The narcotics were increased until the patient appeared calm.”

This is simply an objective way of writing:

“The patient was screaming in physical and emotional agony. Pain, caused by years of bedsores, cancer and pneumonia had finally overrun the pain medication and the patient begged for death. The patient also wailed to his heedless Creator that he had not been allowed to live out his days in peace and happiness and that his family had forsaken him in his time of need. He knows that after he expires there will be no one to remember or care that he had ever lived. With tears rolling silently down my cheeks I increased the patient’s medication since my heart could not bear to hear his cries anymore.”
Which of these descriptions is a better portrayal of death? Clearly the former is more efficient, succinct and practical. Yet, the latter is truer to the visceral experience of death. It is clear that the totality of caring for a terminally ill individual transcends the dry, terse wording of the medical documentation and exists solely on the plain of the emotional and the human.

All of this is very nice theoretical musings, but what is to be done to incorporate the unique elements of the personal experience of each dying patient as part of palliative care? As part of the hospice documentation, there should be included a subjective narrative section that allows for caregivers to communicate the holistic picture of this individual. This would enable others who will care for this individual, such as hospice nurses, volunteers, chaplains etc to read the intimate details of what this individual has expressed and suffered in order to give counseling and medication more effectively.

4- Subjective Cultures

One of the most controversial cases that was discussed was Earl (name fictional), an elderly Asian man who was told by his doctors that it is quite harmful for him to eat anything orally since there was a good chance he might aspirate the food and develop pneumonia. The doctors insisted that he be fed only by feeding tube for his best chance of survival. Many people would abide by this medical advice even if it precludes the pleasure of normal food consumption. Earl's family, however, was not on board and regularly brings him food to eat, even against physicians' orders. In addition, the family gives him therapy themselves rather than sending him to the hospital's therapy staff and ignores almost every single medical directive that they are given. And Earl looks terrific.

Whether his stability was caused by serendipitous dumb luck or is a function of the psychological pleasure of family and food, Earl's culture was completely opposed to bending to the will of the medical community. This raises the following intriguing question:

When does the medical opinion get to predominate over subjective ethics?

In the above case, Earl is responding miraculously to medically inadvisable treatment. However, imagine a more difficult case: A non-verbal patient is actively dying from cancer and associated complications. A family member insists that the patient be fed by a stomach tube until the very end because they believe that it is immoral to let a relative die of starvation. To a physician, this is obviously medically futile since the patient will not improve and will live out his few remaining days in agony. By continuing hydration, one is simply extending the patient’s losing, painful battle. Should this be allowed? Does the
family have the right to say that even extending vegetative life is worth the discomfort imposed on the patient? Adding complications to this, keeping someone alive at this level of dependency is extremely costly. Does a family have the right to use insurance to cover this type of care which is not medically advised?

Essentially, the question is like this: Each culture has its own values, which are subjective. A Hispanic family might place a greater emphasis on avoiding pain while a Russian family might give precedence to extending life at all costs. None of these values are demonstrably superior to any other. There is a medical culture as well- one that develops from much experience for caring for the dying. Does the medical culture have the right to assert dominance over the various patient/family cultures? Is there something inherently objective to the medical ideals that are clearly superior or must they defer to family preferences even when they are convinced the family is acting irrationally?
What is Truth: The First Question from Raphy Rosen, a CSSR-TCC Intern
by Raphy Rosen
June 29, 2010

The field of medicine is concerned with life, yet life cannot be studied without an understanding of death. The CSSR's internship with the Terence Cardinal Cooke Hospital and Medical Center allows undergraduate students to grapple with the ethics surrounding life and death. Each summer two undergraduate students are selected to intern at TCC for 10 weeks. Under the guidance of medical staff, these students conduct research projects that culminate in a final report that presents their work to the CSSR. Raphy Rosen is one of the two undergrads working at TCC this summer. He has decided to chronicle his time at TCC with a series of posts concerning his experiences at the hospital. Below is his first entry, which asks the enduring question: what is truth? But first, we must meet the author, and who better to introduce him than Raphy himself:

My name is Raphy Rosen and I am going to be a senior in CC in the fall. I’m doing a religion major and a computer science minor and (hopefully) going to med school. I heard about the CSSR internship at TCC from friends who did it during previous summers and had a mind-opening experience, to say the least. I am a big fan of the CSSR since it appeals to my two biggest passions, not surprisingly- ‘S’ and ‘R’.

The work here basically involves being mentored by the extremely selfless medical director of Terence Cardinal Cooke Health Care Center. TCC is “729-bed (read: massive) continuing-care facility with a multitude of special care units, as well as two large outpatient clinics.” Their special units include Huntington’s Disease, AIDS/HIV, Alzheimer’s/dementia, end-stage renal failure, severely developmentally disabled children and a nursing home. Basically, this is a rare example of a catch-all facility where you can see a bit of everything. The job involves pursuing projects that the medical director thinks are valuable to the facility but is personally too busy to do. While the lion’s share of our time is spent on these research/staff development projects, we also have the chance to adopt a floor and see what regular life in a facility is like. We talk to residents, aides, nurses, doctors and therapists and try to be helpful in whatever capacity we can. So far in my experience the following is clear: I will do my best to help TCC in some capacity, but they have given me far more than I can give back. The following posts are some anecdotes that I observed. Names have been changed to protect resident and staff privacy. I hope you find reading them to be interesting and rewarding- I can promise you that experiencing them is.
1. One of the things that I have learned in my short time working at Terence Cardinal Cooke (TCC) is that truth is in the eye of the beholder. This maxim comes to expression especially in disputes between residents and staff. Consider the following story:

While observing in the physical therapy room, I struck up a conversation with a female patient in her mid-50s. She told me that she had a Cerebral Vascular Accident, more commonly known as a stroke, leaving most of her left side paralyzed. She had lost the ability to walk and the use of her left arm in a matter of minutes. She described to me her tireless work over the past 3 months during physical therapy trying to regain some function in her left arm and leg. She was proud that after all of her efforts, she was showing some small improvement in her mobility. She confided in me that today was her last day that she was allowed to come to therapy since the hospital staff had discontinued her appointments. In hushed tones she told me that the reason was that she had been too vocal about aspects of physical therapy that she did not like and she was being punished by being barred from therapy. I was appalled to hear that the facility would prevent a woman who so desperately wanted to regain her former life from finishing her recovery.

At the end of the session, after the patient had left, one of the therapists pulled me aside and presented an entirely different account of the events. She said that the patient had been coming inconsistently to her appointments and was not making substantial progress. With the facility’s limited therapy resources, they need to prioritize patients whom they think will benefit from the therapy, so they were discontinuing this particular patient so that other patients could have an opportunity.

Which of these accounts is true? In all likelihood, both are true to a certain degree. If a patient comes to therapy 3 out of 5 appointments in a week, she might view that as the most she is able to do due to her extreme fatigue. At the same time, a therapist might perceive a lack of effort and motivation. While the therapists were not vindictively ending her PT sessions because she complained about their competence, it is possible that if the patient had always behaved cheerful and hopeful, the therapists would see more promise in her progress and would bend the rules to allow her to continue. So what really is the truth?

The uncertainty in this situation raises the ethical question about limiting care for practical or financial reasons. An objective outsider would agree that it is necessary to triage limited resources to favor the patients who will benefit the most. However, imagine for a moment that this patient was your mother. Especially since she is so young, you would do everything in your power for her, even if the odds of success were miniscule. You can understand the frustration of a person who is told that their odds of recovery, though not
impossible, were too small to be worth pursuing. You would feel that the world has given up on you, consigned you to a wheelchair, dependency and life in an assisted care facility. So what would you do? Would you allow her to continue therapy?