

A Place Filled With Love, Life, and Sadness: The Experiences of Residents, Family Members, and Staff in the Huntington's Unit of Terence Cardinal Cooke

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*Note: All names of patients and families have been changed to respect privacy

Introduction

Terence Cardinal Cooke is renowned for its care of people with Huntington's disease. With 48 beds on the unit and a large waiting list, TCC is one of the leading facilities for the care of those affected by Huntington's. Throughout my ten weeks at TCC, I have spent much of my time in the Huntington's unit. The following represents the experiences of some residents, family members, and staff in the unit filtered through my lens, and is a culmination of and reflection upon my own experience in the unit.

The VAP Grant

While a large portion of my project was based on quality improvement on the Huntington's unit at TCC itself, in addition to compiling a reflection of staff, family, and patient experiences, another component of the project was a piloting of the surveys for the VAP Grant, a five million dollar grant provided to New York State to improve the care of neurodegenerative disease across the state. As I was asking the questions verbally rather than by distributing them in written form, I changed the format of the questions to make them more natural when spoken. I did my best to maintain the integrity of the questions and use the same wording. Using this modified version of the surveys Dr. Lechich is spearheading for the VAP grant with some additional questions of my own, I asked the residents' families, the residents themselves, and their caretakers for their feedback on the unit.

The Interviews

As the focal point of my project, I called numerous family members – husbands, mothers, siblings, etc. – to ask them what they would improve about Terence Cardinal Cooke, and also what matters most to their loved one, many of whom are nonverbal and could not communicate this information themselves. I spoke with four residents of Terence Cardinal Cooke who have Huntington's disease, as well as staff that works on the unit.

In the process of speaking with family members and residents, the interviews became a both a dialogue and a reflection, where I got to learn what their experience was like when they found out that they, or their family member had Huntington's, and what their experience since has been. Their openness and testimonies astounded me, and led to some of the most incredible and poignant experiences I have had at Terence Cardinal Cooke this summer.

Although the project began as only a quality improvement study, in the process I had the privilege to get a glimpse into these patients' and family members' stories. In this

portion of the paper, I will try to summarize what they have shared with me as candidly as possible, both in reflecting their experiences with the disease and with TCC. I have changed all names to respect their privacy. The second portion of the paper is my attempt to condense their feedback on the unit, as well as the feedback of staff, into meaningful suggestions. The decision of which information to include was a difficult one: people's stories were so rich, and most interviews ended up lasting an hour. I wanted to paint as complete and rich a picture as I could of the residents and their family members, while at the same time maintaining a narrow enough focus in my paper. I have done my best to find common themes in the interviews, while at the same time highlighting each family's unique experience.

Huntington's Disease: A Family Affair

"You go to family events, and you hope you don't see anyone just moving just a little too much."

-Sarah, sister of two residents, highlighting how Huntington's disease affects the entire family.

Huntington's is a unique illness because it relentlessly affects one family. The emotional toll Huntington's disease takes on the entire family, partially due to the sheer magnitude of people it often affects in one family, is huge.

In the interviews, families expressed their constant worry that someone else in their family, whether it was a child, sibling, niece, cousin, or father, would begin to show signs of the disease. They shared the anxiety and fear that came with the uncertainty of not knowing if and who would show symptoms of the disease next.

Sarah described a unique story where her cousin actually showed symptoms before his father, her uncle. When his son began showing symptoms, his father knew that he, too, must have Huntington's in order to have passed on the dominant gene to his son (the disease was not on the mother's side of the family). Usually this scenario is flipped: one sees a parent's condition as a potential mirror into their future, however this is not always the case.

Nancy, a 92-year old sister of a resident, said that when her sister was diagnosed with Huntington's (they did not know about the disease because their mother died prior to onset of symptoms), she asked her doctor if she could have it, and he told her that she would have already been showing signs. As in many other families, her sister's diagnosis caused her to worry about her own future, or the future of other family members.

"I have two sons... The older one tested himself and he's negative, and the younger one hasn't been tested but he's not showing any of the symptoms, and her brother did when he was 11 years younger than my son is, so I'm hoping that both of them lucked out."

-Edward, husband of resident

For those who have biological children and see their spouse or themselves suffer from the disease, the uncertainty of whether or not their child will get the disease is hard to bear. The healthy spouse is often left in emotional angst.

Mary, mother of Melissa, said that after both her husband and son died from Huntington's disease and her daughter, now at Terence Cardinal Cooke, also had the disease, she could not handle it. Her family had been extremely close, and the disease had shattered this bond. Her daughter became depressed and began drinking and using drugs when she learned she had the disease. Melissa is now nonverbal and very sick, and Mary feels like she has no one left. She moved to a different state in an attempt to remake her life. It is extremely upsetting for her to see her daughter in her current condition. She is planning to fly out to visit for Melissa's 50th birthday, which she says will be a mostly sad. Huntington's disease slams the whole family, deeply affecting even those who are not sick

Anger at the Diagnosis

"It was very difficult the whole time, and she was so angry and trying to hurt everyone."
-Sarah, sister of two residents, describing her sister's anger at her diagnosis.

Huntington's is an incurable and fatal disease. For those who have seen their parent progress through the different stages of the disease, they know the terrible ramifications of a Huntington's diagnosis. When people are diagnosed, they often already have careers, spouses, or children, and their lives have a certain trajectory. The symptoms may progress slowly, but the inevitability of the disease taking over is always there. Family members described their loved one's anger at their diagnoses throughout the interviews.

Sarah said that when her sister, Linda, tested positive, she would not accept anyone's help and tried to hurt everyone who would help her. Although she was still in the early-stages of the disease, the emotional ramifications were extremely difficult for not only her, but also her family.

Marjorie's husband, Edward, described a similar story, although the anger seemed to be manifestation of early-stage Huntington's. He said, "From about 1990 until about 2007 when she got medicated it was very difficult because Marjorie was angry a lot. We got her involuntarily medicated and after that things got a lot calmer."

"[When I found out I had Huntington's disease it was] devastating. It was very hard for me and my family and my friends. It changed decisions about having kids. I couldn't drive anymore, I can't do my nails anymore, I can't do my toes anymore...I can't put my makeup on. Like I can put my hair in a ponytail, but as far as flat ironing my hair, braiding, those kinds of things."
-Kelly, resident

Kelly's onset Huntington's began earlier than most. She was diagnosed in her late twenties, and at 31 is already deeply affected by the disease. Like Kelly, other residents described learning they had Huntington's as "devastating" and "horrible." It was interesting to me that they used the word "we," rather than just "I" to describe learning of the diagnosis, highlighting that a diagnosis of Huntington's devastated not only them, but their entire family. The diagnosis was life-altering and produced emotional anguish.

Anger at Being in a Nursing Home

"Everything about the place makes me crazy. I hate it here, the place itself. I hate that my roommate is 82 years old and I can't speak to her. I have no friends but the staff members."

-Kelly, 31-year old resident

Kelly's life is in Long Island and Florida: her friends, her newborn nephew, her family, her freedom to get manicures and go to bars, people her age. Huntington's disease has landed her here for almost a year now. She feels extremely isolated: she is one of the few verbal patients on the unit. She says she has "acquaintances" from the smoking room, and gets occasional visitors, but resents Terence Cardinal Cooke. She requires the intensive care Terence Cardinal Cooke provides, but hates the confines of the facility. Her unhappy reality is not the fault of Terence Cardinal Cooke, but simply the product of the early onset of Huntington's. Nonetheless, she finds it very hard to be in a nursing home.

"Nobody's here on the weekend. How about me? When do I have a day off? I made a mistake coming here."

-John, resident

John, a 74-year old patient who is still verbal and ambulatory is extremely unhappy to live here. He resents his lack of freedom, and seems to blame the nursing home for his lack of communication with his sons. Along with the anger at having Huntington's comes frustration of having such a stark life change and ending up in a nursing home.

Coping Mechanisms (and Denial)

"The Huntington's I have is very mild."

-Michael, resident with mid-stage Huntington's disease

"There's no such thing as mild Huntington's," said Dr. Lechich. "It's just a matter of how quickly the disease progresses, but it's always fatal," he continued. You could see that Michael's case was not mild. He was ambulatory, but had lots of twitching and cognitive impairment. Outwardly, Michael seemed very happy and verbally expressed happiness and satisfaction with his life. It was difficult for me to decipher whether this affect truly was a reflection of his internal acceptance, or if he was actually really struggling with his condition and life. Regardless, he seemed to have internalized the idea that his Huntington's was mild, and this seemed to be his coping mechanism to deal with such a devastating and uncontrollable illness.

"She's even said that this has been kind of like, I don't want to say it the wrong way, a gift from God because she's a much nicer, kinder person than she ever was."

-Sarah, describing her sister

Linda's manner of acceptance was different. She expressed self-awareness of her physical state, and justified her condition by saying that this had made her a nicer and more patient person. "I was a bitch," she said with a smirk. "I know you were a bitch," her sister confirmed. Laughter ensued.

The bluntness of Linda's self-reflection was made even more poignant by her muddled speech. How does a person cope when physically they are deteriorating beyond anything they can control to the point that they can no longer walk, and it is difficult for them to speak? How do they justify and live with the fact that they have Huntington's disease? Linda's method of coping was to view it as a blessing, as a gift, so that she did not have to live in the rest of her life in existential agony with a "why me?" attitude. She chose to accept and acknowledge her inevitable and present physical decline rather than deny it, as Michael had done, and to justify her condition rather than to fight it, another natural tendency. This justification was not unilaterally hers, but seemed to be the coping mechanism and rhetoric of her family, as well. Sarah's siblings' condition seemed particularly difficult for her to cope with, understandably, and so her coping mechanism, too, was to acknowledge how Huntington's disease made her sister a better person.

Decision to Move to an HD-Specialty Facility

"It's the natural thing, you know? I like being around people with Huntington's disease because we have similar traits. Eileen makes it fun here. She makes it fun here, so it's natural to just want to stay."

-Michael, resident

For the residents at Terence Cardinal Cooke, their needs became just too much for home care and for the family to handle. The family members I spoke to described their decision to move their loved one as a difficult, but necessary, choice.

"I mean she had her own apartment, she had a homemaker before, but after they realized what she had, things like just giving her a bath, and all that, were very difficult because she couldn't help herself in anyway, and I didn't have the energy. She needed the help and luckily we were in the area where they had this help. It was heaven sent, I must admit."

-Nancy, sister of Joan, describing the decision for Joan to live at TCC

Nancy describes finding an HD-Specialty facility like TCC as "heaven sent," especially because she had never heard of Huntington's disease prior to her younger sister being diagnosed. Although her mother had had Huntington's, they had not known because she passed away before any symptoms were identified as Huntington's, which makes sense considering her daughter's onset of obvious symptoms was late, as well. A neighbor, who knew Woodie Guthrie, recommended they go to Columbia University Medical Center, and Columbia recommended Terence Cardinal Cooke, a facility that she had never before heard of. There was an opening, and Joan went.

Marjorie's husband describes a similar scenario. The neurologist told them it was time to find Marjorie a place to live where she could receive more intensive care. After searching for facilities in the D.C. metropolitan area that would accept a Huntington's

patient and being repeatedly turned away, either because they said they could not handle Huntington's or because they would not accept a patient on a Medicaid-pending basis, he emailed Terence Cardinal Cooke, where the social worker and Dr. Lechich responded within twenty minutes. The next week, Marjorie moved to TCC.

The rhetoric of Terence Cardinal Cooke has an accepting haven for their loved ones was common. When no other place would care for their loved one, or give them the care they would need, Terence Cardinal Cooke took their family member in.

Family Guilt: Place Over Convenience

"The biggest thing that I feel I can do now is to visit her, and I feel terrible that I can't [visit more]. Because I know there's nothing I can do for her in terms of the illness."

-Nancy, sister of resident Joan

For many, Terence Cardinal Cooke was selected not for its location, but because it is an HD-specialty hospital, meaning that family members have to drive long distances to visit their loved ones. For others, the emotional ramifications of being part of a "HD family" may make the disease just too hard to bear, leading the loved one to move as far away as possible.

Family members expressed guilt at not seeing their family members enough. When I asked Melissa's mother what she would improve most about the unit, she responded, "I'm not there enough to really be able to comment on that. I live so far away. I think things have improved since she's got there. I don't really know." I could hear both the guilt and pain in her voice even with our shaky connection. Over the course of the conversation I had discovered that her husband and son had both passed away from Huntington's disease, and her visiting her daughter, now extremely sick as well, was very difficult for her. She had moved to a far away state, and seeing her daughter was hard for her to handle. She was planning to visit in August for her daughter's birthday.

When I asked her what mattered most to her daughter, what she really cared about, she responded, "I have no idea what she cares about now because she's not really able to communicate, so to get any information out of her is really very depressing for me. It's not possible."

Another mother of a resident responded similarly:

"I don't know that I would have much input. I haven't been there that much. I really don't know." When asked what matters most to her daughter, she again responded similarly. "I don't know. I really don't know. She can't speak to me, so I don't really know....she used to like to draw but she can't do that now."

"It's very difficult, but I felt that it was better for her to be in a good place rather than my convenience. It's very hard for me to get into the city, but at least her daily living conditions are better...You see it's hard for me because I'm handicapped and I travel on a scooter, so it's difficult for me. I try to get there like once a month but this past month I wasn't able to go. Hopefully, if the weather's okay Sunday, we expect to go. And her daughter always comes with me."

Nancy, Lorraine's sister stated, "Up until this year I went every week to visit her, but the weather was so bad and another sister passed away, and I'm too old to drive. So therefore, I haven't visited as much as I would've liked....The biggest thing that I feel I

can do now is to visit her, and I feel terrible that I can't [visit more]. Because I know there's nothing I can do for her in terms of the illness."

"I found out I was adopted right around the same time daddy was diagnosed, but at that time, I felt so guilty that they could be sick, but I wasn't. But then being adopted, I don't have any history, you know what I'm saying?"

-Sarah, sister of residents Linda and George

Sarah had a different kind of guilt. When she discovered that she was adopted and therefore did not have Huntington's, she felt immense guilt that she could not get sick. Although, as her sister teasingly reminded her of, she has her own medical problems that she has dealt with over the years, which she says raise their own problems, she still felt the weight of being the only sibling with no possibility of having Huntington's. Their older brother, although a biological sibling, is also negative.

Dedication to Partners

"When your legs don't work like they used to before, and I can't sweep you off of your feet, will your mouth still remember the taste of my love? Will your eyes still smile from your cheeks? And, darling, I will be loving you 'til we're 70. And, baby, my heart could still fall as hard at 23."

-Ed Sheeran, Thinking Out Loud

Linda had only been recently diagnosed with Huntington's disease when she met Ken. At first fearful to tell him of her diagnosis, thinking he would leave her, her sister Sarah convinced her to tell him after they had been dating for three months. Eight years later, she has an opal engagement ring and he visits her multiple times a week.

Anne's husband is no different. A Wall Street banker, he visits her on the way to work or on the way home almost daily.

Marjorie's husband is no different. Although he lives in Washington D.C., he takes the Amtrak, for which he works, once a week to visit her.

Even with a debilitating disease like Huntington's, where loved ones often can no longer communicate or act like the person they used to be, partners stick with their loved ones.

Quality Improvement: The Good and the Bad

Better Entertainment for Non-Structured Recreation

"Sometimes it seems like Marjorie's just sitting in the dayroom watching TV a lot, or maybe not watching it; maybe just sitting there."

-Edward, husband of resident

With a disease like Huntington's, where the majority of the patients on the unit are confined to wheelchairs, many patients end up spending much of their time in the dining room. One major worry was entertainment of the patients while in the dayroom. One husband of a resident said that his wife spends the majority of her time in the dining

room, partially he thinks because the sound on her own television is not working. In the dining room, he says, the televisions are very small and far away from the patients. He says sometimes it seems like she is “just sitting in the dayroom watching TV a lot, or maybe not watching it; maybe just sitting there.” He acknowledges that his wife often does not want to take part in the activities they provide, and that this is not the fault of the facility, but wishes that the televisions in the dining room could be updated.

The recreational therapist, when asked for three improvements she would make, had a similar suggestion. Many residents spend the majority of their time sitting in the dining hall and watching television, however the current setup is such that there is one television at the end of the room. When this is many residents’ main source of entertainment and their main daily activity, not having good access to the television is difficult. She suggested adding another television to the room and repositioning the two televisions so that they are on each side, allowing the residents to better be able to see the television. She also suggested getting new stereo systems for both units (North and South) so that the sound is better. Minor improvements can make a huge impact on the unit and the quality of life of the residents.

Lack of Communication with Families:

“I don’t particularly care for the room that she’s in. This is her third or fourth room... There was no real reason that she was moved. I think it because of the need for someone else to have that room; that’s all I can think of. I don’t really know any other reason.”
-Nancy, sister of resident

Nancy commented that she was unsure why her sister was switched to a smaller room. She says that the only reason she can think of is that someone else needed her room. The progress note, however, written by the social worker, says that the resident was switched to a larger room to better accommodate family visits.

Sarah commented that when her sister’s medications were switched, neither her, nor her sister’s fiancée Ken, were notified, even though they are her health care proxies. She also commented that it is often difficult for her to get information from staff members. She says that she will sometimes ask a nurse a question, and they will direct her to ask someone else, saying that a different nurse will know, and that nurse thinks that another nurse will know. She says sometimes you get the “runaround.”

Deborah, her daughter’s health care proxy, commented that she had repeatedly told the staff that she did not want her daughter taking a certain medication, but they did not seem to be listening to her.

“I know they know way more about Huntington’s, medically, but I know Karen, and I know what didn’t work, and what got us where we are now,” she said. I asked the social worker who said that she was aware that she did not want her on this medication, and that Karen had never been on this medication, and she followed up with Deborah, who confirmed that the staff had taken her suggestions seriously. Once, however, I had witnessed Deborah come to the nursing station extremely upset that her daughter was on a particular medication that she had said she had explicitly communicated to the staff she did not want her daughter on. Perhaps her upset at this one medication was simply a manifestation of all her anxiety and angst about her daughter’s condition, as well as a

reflection of her memories of her daughter's previous hospital experience, where the staff had not listened to her. Whatever the reason, she felt that the staff was not listening to her.

Worry of Lack of Supervision

"...on several occasions I've gone in and...there has been nobody on that ward, from the first room to the lunch room, and she's in there in her room, in a chair, strapped in, and there's not a soul around, and that's dangerous. So, staffing is definitely an issue."

-Deborah, mother of Karen

Family members worried that there was insufficient staffing on the unit, leading to a lack of supervision. They commented that, particularly in the dining area, they have found their loved ones without any supervision at various times. This does present a safety issue, and should be addressed.

A Barrier to Visits: Transportation and Parking

"It's impossible to park. It works out to be a nine-hour day just trying to visit her."

-Deborah, mother of resident

Visits from family members and friends are often the highlights of their time spent at Terence Cardinal Cooke. The parking lot was condemned and closed, making parking for visitors extremely difficult. Many families expressed that since they closed the parking lot, looking for parking can add as much as two hours to their already long commute to visit their loved one, making the drive burdensome. This seemingly small issue of parking reduces the amount they visit their loved one, decreasing the quality of life of the resident, who deeply values the visits. A family member of a patient who has been in the facility for nearly eleven years, who visits his wife three times a week, remarked, "They closed the parking lot and it makes it harder to find spots to get into the nursing home. It's a big problem. Sometimes I have to wait two hours to try and get a spot."

Another mother of a patient remarked, "We don't get there as much as I would like. It's impossible to park. It works out to be a nine-hour day just trying to visit her because we live on Long Island. It's been taking two and half to three hours to get in, and then we have to find a parking space, and then a three hour ride home, so not including the visit, it's really, really tough. All of my family members are finding the same thing."

Another sister said, "And also, after I do drive, even though I'm not supposed to, there's no parking because they took away the parking lot."

This barrier to family visits is a large one and greatly affects patients. One young patient lamented that she wishes she could live closer to her brother, sister-in-law, newborn nephew, and aunt so that she could see them more. Due to the fact that Terence Cardinal Cooke is far away from her family and difficult to get to, however, and the fact that they work full time on top of juggling a new baby, they rarely visit her. She says if she were closer to them they would take her out more and she would get to see them.

More “Nudging” From the Staff to Be Active

“...so yes, they’re respecting her wishes and her space, by saying, you know, ‘okay, she doesn’t want to get out of bed, we’ll leave her there,’ when I’ll say that she promised me she was going to get out of bed every other day for an hour.”

-Sarah, sister of two residents

Sarah’s sister Linda tends to stay in bed. Sarah says that Linda promised her that she would get out of bed for an hour every other day. She says that she called Linda and asked her if she was out of bed, to which Linda replied that she was not. When Sarah asked why she was not out of bed, Linda said that she had told the staff that she did not want to. Sarah feels that staff does not motivate Linda to get out bed, and they have told her, “Sarah, she only gets out of bed for Ken [her fiancée]; she’s not going to get out of bed for me.” She worries this attitude is detrimental to Linda’s health, and thinks that with a little more encouragement, Linda would get out of bed more.

A nurses aide expressed something similar. She said that “The patients are so used to being in the dining room or the bedroom that many of them say no at the offer to take them out” and that “Sometimes, so they can just see what is out there, they should be taken anyway. Or, people should go out more so that they see what is out there.”

There is clearly a fine line between respecting patient’s refusals and wishes and encouraging patients to be active, to leave the dining room and their bedrooms.

I myself witnessed a more extreme example of this dilemma between respecting patients’ wishes and encouraging them to go outside their comfort zone when staff believes it is best for the patient. Another resident, Ben, prefers to rarely get out of bed and can become physically violent when taken out of bed. Staff determined he should get out of bed. This was not, however, effectively communicated to the nurses and nurses aides, and when I went to the unit to sit with him, he was still in bed. I went and asked the CNAs if they were planning to take him out of bed, and they were first, unaware that he was supposed to get out bed, and second, fearful of getting him out of bed by themselves. “It is not my job to be hit,” one said. Another said, “he gets out bed easily with his mother, but with us, he bites and is aggressive.” They said they needed a male to help them, and were clearly scared for their own safety.

There seemed to me to be a disconnect, a certain lack of communication, between the wishes of the directors of the unit and the nurses and nurses aides. There also seemed to need to be a more organized strategy implemented for situations in which the patient is physically violent.

Later that afternoon, I came back down to the unit after a staff member called me to say that they had gotten him out of bed. When I got there, the patient was extremely agitated and kept repeating, “back to bed, back to bed.” The CNAs brought him back to bed. There is clearly a fine line between going against patients’ wishes and encouraging the patients to be active.

Linda’s brother, George, can also be physically violent. “He hit Dr. Lechich once,” Linda said. When I went to interview George, a custodian who worked on the unit motioned to me, “no, don’t.” He later said, “he gets very violent and sometimes hits people, and I didn’t want him to do the same to you.” I did not heed his warning, and had no problem, perhaps because I interviewed him in a social environment, perhaps because

his moods are mercurial, or perhaps for another reason. Sarah, George and Linda's brother, wishes that staff would not be so fearful.

"He can say, 'I'll hit you,'" and "so I think they don't engage him," she said. She says she thinks this leads to his lack of cleanliness and wearing the same clothes for many days in a row, which she finds particularly upsetting. To her happiness, he still gets shaves and haircuts.

Linda's situation is different from George's or Ben's, however all three examples demonstrate the fine line between respecting patients' wishes and encouraging them to go outside their norm. Whereas in situations like George's or Ben's, perhaps the patients are better left alone, more moderate situations like Linda's could perhaps use more encouragement.

Floaters:

"I hate floater CNAs because...they just don't take good care of us...they don't do the right thing: like falling asleep in the shower, like dropping washcloths on the floor and picking them back up and washing my body with them, those kinds of things."
-Kelly, resident

Residents, family members, and staff expressed concern about "floaters," non-regular staff on the unit, particularly nurses and nurses aids.

A nurses aide who regularly works on the unit commented that the floating staff is often not patient with the residents on the unit, which deeply upsets her. She said that they often are not prepared to work with patients with Huntington's patients. She gave the example that if a resident refused to eat at first, they might immediately give up, meaning the resident would end up not getting fed. Residents often require patience in order to eat, and she implied that the floating staff often does not have a good understanding of, and sufficient education about Huntington's disease. Additionally, the floating staff would come on the unit without knowing the patients, causing confusion and decreased quality of care.

Arthur, husband of resident Barbara, commented, "The only thing she doesn't like is the floaters. She likes the people that she knows the most. When some of them are on vacation ...Mostly they try to accommodate her so that she doesn't get a floater."

Resident Kelly expressed great anxiety that a nurses aide whom she had become very attached to was retiring and moving back to the Caribbean. Many residents take great comfort in seeing the same people regularly, and not only do the floaters make them anxious, but they feel that they give them a lesser quality of care.

As floaters are necessary financially, measures need to be taken to better their caliber and provide better training for them because they clearly are not going away. The creation of ADL cards was an initial step, but more can be done to ensure that the floating staff treats the patients with the same dignity and patience that the regular staff does.

A more hands on component of my project was creating ADL, Activities of Daily Living, cards for the patients in the Huntington's Unit, which was asked of me by Jeanne Thomson. The cards would serve as "cheat sheets," to quote Jeanne, for the floaters, something that they could put in their pocket to refer to. Making the cards was also a wonderful way for me to get to know the patients and the staff on the unit.

ADL cards, however, can only go so far. Knowing a resident's toileting, eating, dressing, communication, and any special behavioral patterns is extremely important, but does not make up for, or immediately compensate for, lack of patience or gruffness with the residents. By virtue of the fact that floating staff does not spend as much time on the unit, there is understandably less connection with the residents, but again, this cannot be an excuse for laziness and gruffness.

Floating staff, prior to working on the unit, should be better oriented and prepared, and also vetted, as this is an extremely special unit that requires special people.

Appreciation of the Dedicated Staff

"You know the fruit cups? I can't open them. So whenever she's here she opens my fruit cups for me."

-Michael, resident, describing a CNA he is close to

It was evident throughout the interviews that there was great appreciation from both residents and family members of the dedicated staff members. Patients and families overall expressed that the regular staff was dedicated, patient, and respected their or their loved ones' personal dignity.

Food:

"I wish they gave us fried chicken. I like Chinese food. I don't get that."

-George, resident

Patients expressed a desire to have more variety in their food options. Three patients who feed themselves and are on a regular diet commented that they wished the food were better and that there were more options.

For those on a puree diet, the dietician suggested that there were more puree options. The dietician also suggested a puree, honey-thick, high-calorie supplement for people who are losing weight. She suggested some sort of powder or other alternative to the frozen nutritional treat residents currently eat.

Feeding:

"Out of 24 patients on the South Side, only four people eat by themselves."

-CNA

Feeding a resident can take an hour. Not only does this cumulatively take an extremely long time because there are not enough feeders, it is also physically grueling for the CNAs. CNAs expressed that it was difficult for them to feed the residents because the chairs for them to sit in were too low, meaning they ended up standing for long periods of time because of the length of the feeding. Simply getting high chairs for the dining room for the CNAs to sit in would make feeding easier for them.

CNAs also requested more help during feeding times, simply because of the length of time feeding a single patient can take.

Clothing and Laundry:

“...there were times that I would get very upset because I would come in and he would be wearing the same clothes... so that’s been a concern with Hughie’s state of appearance and hygiene. He showers everyday, but I don’t think he’s using soap.”

-Sarah, sister of residents

Numerous staff members commented that clothing and laundry on the unit was a large issue. Clothing is frequently mixed up between residents.

Staff commented that the nurses aides who have the night shift are supposed to put the residents’ clothing into their respective closets. When the morning nurses aides come, however, they find that the night staff has not done this properly, slowing the morning shift down and taking time away from other valuable tasks, such as sitting in the dining room with the residents.

One CNA commented that the residents who do not have present family do not have appropriate clothing to wear. She said, for example, that many patients do not have shorts for when it is hot outside. She stressed that this is a matter of basic human dignity.

Many residents complain that when they send their laundry out, they do not get it back, and one family member noted that she was upset that she saw her brother wearing the same clothes multiple days in a row. She acknowledged that this may be a function of his dementia rather than the staff, but still stressed that she found this clothing repetition extremely worrisome.

On the Huntington’s unit, a seemingly basic matter, clothing, has become a matter of much concern and anxiety for staff, residents, and their families.

Recreation:

“It’s good, yeah. They need that. They need something to make them wake up. I think there should be more for them, though. But some of them refuse to go; they don’t want to be bothered.”

-CNA

Recreation, overall, was lauded by both residents and family members alike. In particular, they complimented Eileen, the recreational therapist. One patient commented that she was “terrific” and “sweet.” Nancy, a sister of a resident, commented, “I think [Eileen] is wonderful really, her sensitivity to the patients, the good spirit she has.” I have seen Eileen’s energy light up the room, but Eileen is not always there.

Some staff articulated, however, that there should be more activities during the evenings and on weekends for the residents to participate in. Residents said that there was not enough staffing on the weekend, and expressed a sense of loneliness during these times. When staff clears out in the evening, there is a halt in activities, but the life in the unit does not stop.

Finding Haven at TCC

“[Terence Cardinal Cooke] know[s] what they’re dealing with, which is what they didn’t know at the psychiatric hospital.”

-Shirley, mother of resident

“[Dr. Lechich has been great about] understanding his needs and his anger issues, and really trying to create a program with George that allowed him to be here, with Huntington’s, where, a lot of other nursing homes might have kept him, or left him, to be in public facilities because of his outbursts.”

-Sarah, sister of residents

Family members complimented TCC for accommodating residents’ psychiatric needs in a way other facilities had not. TCC combines their understanding of Huntington’s disease with their understanding of the psychiatric manifestations of the disease in order to create effective and meaningful care plans for its patients.

Confidence in Terence Cardinal Cooke, an HD-Specialty Facility

“Having things that they can enjoy looking at, and being comfortable, and still living a life, is so important ... it’s about living with Huntington’s...that’s what we find at the Cooke center. It’s about living with Huntington’s.”

-Sarah, sister of residents

Both family and patients expressed confidence in the Huntington’s unit at Terence Cardinal Cooke. They said that the staff at Terence Cardinal Cooke was knowledgeable about Huntington’s Disease, and that despite the long distance family members had to travel, it was worth it to be in an HD-specialty nursing home. One mother of a resident remarked that she chose Terence Cardinal Cooke because they “knew what they were dealing with” with regards to Huntington’s Disease, something that the resident’s previous facility, a psychiatric hospital, had not. Despite the distance the facility was from her home, she said being in a place like Terence Cardinal Cooke made the travel time worth it. When a sister of a different resident was asked if she had any additional comments, she said, “We’re very thankful for Cardinal Cooke. We wouldn’t be able to manage without it.”

One husband of a resident remarked, “This is a unique disease with its own real bad challenges, but the staff seems to be trained in it.” The husband described his experience in selecting TCC for his wife’s care. When his wife’s neurologist in Maryland told them it was time to find her a safer place to live where she could receive more intensive care, he searched for places in the D.C. suburban area. Every place he found, however, “couldn’t take someone on a Medicaid-pending basis” or “had no idea how to handle Huntington’s disease.” He finally emailed TCC, knowing they were an HD-specialty facility, and received an email back from the director, Dr. Lechich, 20 minutes later, and an email back from the then social worker ten minutes after that. They recommended a lawyer to help with New York City Medicaid, and the next Monday, his wife moved into the facility, where she has lived for nearly three years. He says that the staff at TCC is very dedicated, and that if someone cannot help him right away, it is because they are helping somebody else.

There was a consensus the staff was knowledgeable about caring for people with Huntington’s, amongst patients, staff, and family.

These Are a Few of My Favorite Things: What Matters Most

"I know that even though she can't talk or do much of anything, her eye movements show me that she's very glad when I come to visit her."

-Nancy, sister of resident

The question, "What matters most to your loved one," is a difficult one when your loved one is unable to communicate this themselves. I asked each family member I spoke with what they thought mattered most to their loved one, based on the suggestion of Carol Moskowitz, MS. The idea was that what was most important to their loved ones could be translated into improving their care.

"What matters most" to residents can often get lost in the daily monotony, and chaos, of changing diapers, feeding, dressing, etc. The question of what mattered most to their loved ones often elicited the most emotional response, particularly when what the family member mentioned they loved was something they could no longer do, like drawing, or when they felt they could not really tell because their loved one was nonverbal.

Everyone I spoke to, however, mentioned how important it was to their loved ones when people visited them.

Edward, husband of Marjorie, described how much his wife brightens when her church's clergymen come to visit her, and when himself and their son come. Shirley describes how much her daughter, Francesca, loves it when her own 11-year old daughter comes to visit. Kelly described how much she looks forward to the visits of her family and friends. Sarah described how much Linda loved her fiancée Ken's visits.

"Like, she's happy to see me, but she wants to see pictures of Ken. When I come, it's like, ok that's great, but let's call Ken. [Linda grins]. Well it's true," she teased. "At least I don't get offended."

My Conclusion

In my time spent in the Huntington's unit at Terence Cardinal Cooke, and in speaking with the residents and their families, I've seen how much pain the disease inflicts on both the family and the individual. I've also seen how much life there is in a single unit, and how this life can be maintained. Terence Cardinal Cooke does a wonderful job at this, and the work and dedication of the unit is clearly appreciated by residents and families. As one CNA I spoke with said, "There's a lot of life they leave behind them here; they're going to be here for the rest of their life and I like to do whatever I can do for them [to] make sure to make them happy." I think this beautifully depicts the feeling of the unit.