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## Odd harvest

### Reflections on the practice of brain collection

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Brain donation is an unusual pursuit. It is an aspect of medical research that the lay public may not necessarily know much about. In 2003, to learn more about the underlying pathophysiology of essential tremor (ET), we established the Essential Tremor Centralized Brain Repository (ETCBR) at Columbia University, a research effort whose purpose was to enhance understanding of the ET brain (NIH R01 NS042859, Elan D. Louis, principal investigator). Now, at a 10-year point in this endeavor, we pause for a moment to reflect, distill, and share. Why? From the moment potential brain donors first inquire about the possibility of donating their brains to science, all the way through the long course of postmortem brain tissue analyses, health professionals are involved. They experience a range of emotions, thoughts, and reactions, yet we are unaware of any literature that has attempted to capture and record the human elements of this process.

The project coordinator, Art Gillman, fields initial telephone calls from curious prospective brain donors who answer an advertisement about brain donation, which we posted on ET support group Web sites. If they meet the criteria and are still interested, Mr. Gillman mails them information on how to enroll. In our Repository, he also conducts in-person clinical assessments and periodically collects updated information to see whether the enrolled donors' condition has changed. He is sometimes referred to somewhat wryly as the "Welcoming Committee." He writes:

As project coordinator of the ETCBR, I spend long hours on the telephone with our approximately 250 living ET brain donors, ages 70 years and older. When I call them for updated information, we often go through the same humorous back and forth: "Sir, I'm not dead! You can't have my brain yet," they tell me. I assure them, "I'm not here to collect."

Before I took over as project coordinator several years ago, I was traveling around the country conducting clinical assessments with our future brain donors. In this 2-year process, visiting more than 40 states, I experienced car accidents, a deer in the headlights, bed bugs, epic snowstorms, numerous flight cancellations, a shakedown by a customs officer, and even a study visit to a nudist resort. I was committed;

nothing stopped me in the pursuit of data. I was initially dubbed "The Grim Reaper" because a few geriatric brain donors died shortly after my visits with them. To cheer me up, one of my coworkers quipped, "You are like the Horse Whisperer, except with elderly curmudgeons."

A nonagenarian brain donor insisted that I come visit her for a clinical assessment. I was hesitant. Would she have the stamina to endure several hours of questionnaires, a rigorous walking assessment, and a videotaped examination? Persistent as she was, I finally agreed to fly out to see her. She was huffing and puffing the entire time, even with the help of her portable oxygen concentrator. Within 10 days of my visit, however, she passed away. I was heartbroken and spoke to her next of kin, who said that I shouldn't feel badly; brain donation had been her dying wish.

I have built a special rapport with our ET brain donor community over the past 5 years. I inherited 200 shaky grandparents. Watching dozens of them die year after year is a morbid, difficult part of my job; it is one that doesn't get easier over time.

The autopsy facilitator, Carol Moskowitz, works on setting up a preplan for the newly registered brain donors. Internally, the term "tuck in" is used by us to refer to this process. She finds local pathologists willing to perform the brain tissue procurement and mails instructions and sample buckets/boxes/cooling packs to them. She also coordinates with chosen funeral homes, which will transport the donor's body to the appropriate facility, so everything goes smoothly when the donor dies. Furthermore, she builds rapport with the brain donor and the next of kin. She is the one paged in the middle of the night, at the time of death. The next 4–6 hours are spent arranging smooth procurement and transport, fielding urgent calls with next of kin, obtaining consent (using a bonded telegram), and holding discussions with local pathologists, transporters, and couriers. Carol reflects about what she refers to as "essential silence":

To fall into silence at the end of all the paging, phone calls, faxes, and e-mails allows the next of kin and autopsy facilitator time to reflect. This silence

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both staves off the grieving process and at the same time announces it. The quiet calm of deep snow finally fully fallen. Silence suspended between 2 people, only strangers hours before, acknowledges that in the rush of words and actions something profound has occurred. Frequently, after I am done, I walk outside, looking for the moon. I just stand there letting go or wishing without words, feeling grateful.

The brain arrives at our facility iced in a bucket, where it is carefully processed by one of several clinical neuropathologists. Phyllis Faust writes:

Brain banking is a complex procedure. In a world of obsessive cataloging, technical prowess, and incredible precision, brain banking is entrusted only to the most trained hands and observant eyes. The challenges are numerous. Even Jell-O has a firmer consistency than the brain before fixation. Thus, preparing fresh slices is technically challenging and truly an art form that is respectful of the person's donation. This initial "precise carving" of the fresh brain and time-consuming tissue preparations take several hours but provide invaluable unfixed tissue for modern molecular analyses. The entire brain is examined and taken apart, with different areas frozen, fixed, sectioned, and stained for microscopic changes, allowing for diagnoses to be generated and experiments to be fueled.

My son proudly touts in his fourth grade class, "My mother cuts human brains!" I enjoy an odd esteem among strangers, but it is quite another thing to appreciate the ultimate decision of donation, the ramifications around brain procurement and processing, and our sense of obligation to these individuals and their loved ones by making sense of the unknown. As I am reminded by these donors' contributions, the pursuit for answers becomes all the more consequential and compelling.

The tissue then falls into the provenance of the laboratory technicians, Rachel Babij and Michelle Lee. Like the neuropathologist, they are removed from human contact. They only know the donor in the form of brain tissue, which they analyze.

The opportunity to assist human brain research is a glamorous thing to young technicians who are looking to break into medicine. Human tissue affords direct clinical relevance and a promise to illuminate consequences of disease. The brains we work with are precious, limited, and tremendously important donations, and we treat them as such.

As technicians, we pass hours in the freezing microscope room on a daily basis. Wrapped in sweaters and surrounded by brain slides, we get lost in the amazing blooms of Purkinje cells of the cerebellum. Studying these uniquely large cells with lushly developed dendrites, we stain, trace, count, record, and

analyze axons and cell layers. Words like beautiful, noteworthy, and God only knows what that is, creep into descriptions of processed autopsy tissue. We frame pictures of rare axonal swellings on the wall, admiring their acrobatics within micrometers of tissue.

This is in stark contrast to our first day, when, after years of studying dull neuroscience textbook figures, we hesitated before reaching inside the brain jar. Grabbing the long brain-cutting knife, with the mix of eerie mortification and excitement, we held a glistening beige cerebellum for the first time. The firm ridges and intricately folded interior are now as familiar through our blue gloves as the sensation of holding a baseball.

However, from the beginning, these brains arrive to our lab with just an accession number. Blinded to donors' names, faces, diagnoses, and any life history, we sometimes forget these cells functioned in actual people, particularly when we spend most of our time looking at cellular details under 600-fold magnification. That these cells belonged to a 78-year-old woman, orchestrating her gross body movements, buttoning a cuff, or shakily reaching for a glass of water, are momentary, if somewhat uncomfortable, thoughts in passing. It is far easier and rather fascinating to focus on the colorful stains in the eyepiece.

After leaving the microscope room, the gnarled trees on the way to the New York City subway look like eruptions of Purkinje dendritic arbors, the cell body planted just beneath the concrete.

The principal investigator, Elan Louis, is the overseer. This process is his brainchild.

Setting up a nationwide brain "donation" program is an odd proposition. Indeed, it is a peculiar sort of thing with which to find oneself involved. Even the words brain and donation don't slip off the tongue together easily—improbable linguistic bed partners.

Brain donation—this is an intensely personal possession, which people are handing over to us. After all, the brain has traditionally been viewed as the very seat of the mind and the soul. Memory, logic, and reasoning are among some of its more mundane products. Creativity and emotions are the broncos. And then, of course, there is the intangible—the "person" behind the person.

End-of-life discussions might seem uncomfortable to some at first. The conversation carries within it the formal recognition of mortality. One is facing death, and not merely in a vague and distant sense. While it seems macabre, this is actually a conversation that is all about hope.

I was never trained in medical school to do this sort of thing. You can stop a conversation dead (no pun intended) at a cocktail party by announcing, "I run a

brain donation program.” There are the initial quizzical looks and then those who uncomfortably avert their eyes, hesitantly taking a stab at the guacamole. After a second or two, though, most people are intrigued to find out that they live in a world in which there are scientists who are intensely interested in pushing the boundaries forward, and that they are teaming up with patients who have suffered from an ill-defined problem for years or even decades.

I am the interpreter. The 2 teams never meet: the patient and family on one side of the line—their questions unscientific, personal, and sometimes built of the stuff that reaches up into the cosmos. Then there are the scientists. They are dealing with tissue, postmortem intervals, and so on: details that can only sometimes be visualized under a microscope. Picking, exploring—carefully descending deeper into the labyrinth.

I sometimes hear from the children of donors, after death, most of whom don't know why their mom or dad had this strange request, but nonetheless

respecting it. Those who have handed over the organ rather than clinging to it, all in the name of love. Discussing their parent's wish to be helpful to science and to future generations and letting them know that we have learned a great deal from what we observed in their brain; this is rewarding.

The gift of donating one's brain to advance scientific knowledge is a generous, selfless act. It takes a unique partnership: the willingness of potential donors, who can visualize parting from their anatomy and muster up the courage to make that initial brain donation inquiry, and the corresponding health professionals who see this noble process through. While brain donation may still be considered odd, public perception has evolved over time, making brain donation more understandable to the masses. Recently, a future brain donor joked, “I decided to become a brain donor because this is the only way I would ever get into Columbia University.” Clearly, his heart—and brain—are in the right place.

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