

Chapter Nine

Between “I” and “(I)nc”

How (I)nc. Think

“What I want is to help as much as I can,” says George, 73, “to give my experience and my way of looking at things, which is not necessarily the *best* but, like I say, this is it.

When I noticed that Cecelia was becoming Alzheimer, her own doctor tried, you know, that medicine called Coñex?” “Cognex,” I say. “Cognex,” says George, and then, ugh, but *one thing*, the number one thing in my life, is that I trust God, okay. He never fails. And then, for reasons unknown, Cecelia being healthy as a human being can be, she *refused* to have those pills, and those pills she hid, she put em away. I’d give em to her, she’d make me believe she swallowed it and then she threw it out. Then I started finding them all over the house. She took only ten pills at the most. And that’s when I first started experiencing Alzheimer’s. For reasons *unknown* to me, that is something I’ve never been able to learn, is how Cecelia was picked-up by the University of Miami to be in a test of a new drug. Now, what they did with her, with this medicine or whatever it may be, they put her in a test. Was it a placebo or whatever we didn’t know which one it was? But then we learned that the medicine was stalling the progress. So, ever since, everyone has been *so helpful*, and then they recommend me, because I start experiencing this, I didn’t know much about Alzheimer’s and then I was *lost*. I dealt with Richard, and you see what I got out of Richard, and that was a different experience altogether.¹ So, I

¹ What George is referring to here is a complex situation about which our entire conversation is concerned. Most directly he is referring to the fact that his adult son Richard has Down’s Syndrome. Beyond this,

had to go, by myself, to a psychiatrist, and then I told him what my experience was, and he told me ‘George, what you ought to do is take this medicine and buy yourself a pair of roller skates, get

those little wheels in the roller skates, and put em in the bottom piece of the cross so it will

be easier for you to carry.¹ From now on, there’s no way out.’ That’s what the psychiatrist told me. And then I told him, I said, ‘Well, listen, my other son, he’s in California, and there’s absolutely no way I can impose on him, this situation, because it affects *me*. How will it affect him? I dunno. So that’s when I told him, ‘If *ever* I learn that anything is going to happen to *me*, his brother being in California, I will go, and never in my life have I used a gun, never, okay, not for fun, not for practice, not for nothing. I held a gun once in my life and that was it. But the decision was made, if anything happens to me, I won’t let Richard be, you know, moved from one place to another. Cecelia, she got the run of her life already, so what I will do, I’ll *kill them*, and then I’ll kill myself, simple as that.’ And then that’s where this psychiatrist ‘Oh no!’”, says George, acting out his state of alarm, “but what I was facing was *reality*. His brother was not at all motivated to come so, what use, if I’m not here, I’m not gonna leave Richard, no, he’s an *angel*. And the only single thing that keeps me going, the most important, is *Richard*. Cecelia is not hope, but Richard is my life. So when the

however, he is referring to what I know of Richard personally, having spent time with both of them on previous occasions. Although it may not appear to be, this conversation is about Alzheimer’s and how to think through and deal with it, but it takes the form of a description of life experience and adapting to adversity in a very beautiful and thought provoking way.

psychiatrist heard me, and he went ‘OHHHHH!’ I wasn’t a killer or suicidal, no no no, what I’m facing is reality. Anything happens to me, I am an animal and when it’s cornered it will *fight*, so that’s the only solution.² But God helps me, so then this is when Cecelia was picked up by the University, and through the University they sent her over to the daycare center.”

George likes to leave it a mystery as to how his wife was “picked up by the University.” To him there is the air of a miracle involved, and although he said he has “tried to find out” how she came to be a test subject and under the care of the University, he really never has, and likes it that way. Of the daycare center he says: “Cecelia being here gave me relief. The meaning of my business is for Richard. Richard doesn’t sit and look at the world ever.³ So I’ve been to several places in which they deal with retarded people, and what I saw in every place was sorrowful, very bad, and I said ‘There’s no way Richard can go to one of those places. If he worked with me, they’re gonna respect him, because he’s the son of the owner. You know I don’t make anything, not a penny,”

¹ It is thus that George begins a tale that moves from self-sacrifice and beyond this first attempt at symbolic incorporation. It is in shrugging this cross that George begins his story, meeting a philosophy of violence and servitude with a philosophy of dialogue and transgression.

² Here we see an interaction in which the meta-linguistic and the linguistic aspects of Alzpeech collide, and in which a strange form of mimesis comes into play, a form in which one erotic move toward the Symbol and Christology is met with another transgressive language of sacrifice. “Take the cross upon your shoulder”: says the psychiatrist (a curse no less powerful than the one in Kafka’s tale *The Judgment*) and give in mimesis what is owed to your father, for humanity—to which George responds negatively. ‘I am the father,’ says George in transgression, ‘I am an animal and I’ll kill them rather than let you or the Symbol have them.’ And the psychiatrist, being transgressed against, utters, as if witnessing a sacrifice, “OHHHHH!”, imagining and/or miming either his own sacrifice, that of George, or both.

³ It is as if, one might say, interior *logos* is always active, as one also sees in *dreama*—this *logos* in continual transgression against the exterior *logos* of taboo. In a certain sense Richard exudes an *excess* of this activity which transgresses against those who deal with him, an excess which is as unsettling as it is alluring, obscene as it is lovable. To watch him deal with those in the daycare center when he would visit

he says with a whisper, “it’s mostly to cover costs. But Richard works there and he really looks forward to it. He talks to people, he goes around and does anything you can imagine. There’s nothing you can teach him that he will not learn in a second. Everybody has to respect him, okay, that’s most important.”

After going through a seven-year divorce in California his oldest son returned to Miami, with several problems and a little girl, to live with the family. “Now I’ve got two baby girls, and two boys,” says George, “plus the factory. But somehow, one way or another, I know that to bring my son back to normal will take some doing. You can’t do it overnight. But now he’s here, and he’s not going to leave, and he’s met with Richard and found that *Richard is JOY*. Richard creates no trouble, he demands nothing, he gives you *love*, pure, unremitted, *love*. So now he looks after Richard.”

“Richard helps me with his mother,” says George, “in so many ways. He loves details, tiny little details he will remember. It’s like those people who killed themselves not too long ago, that cult or whatever, where they can communicate with the master, through writing, Richard, when he wants anything doesn’t come and tell me, but he writes me a note. And when he writes me a note it’s like when he has regarded anything that may go wrong, that doesn’t work, or whatever, he *knows* me. That’s the way he is. So in my life

was truly a remarkable thing. He seemed to know these people better than anyone, to know them as a people in the way no ethnologist ever could.

it's number one to try to give him as much as I can as long as I'm alive. I'm not sick. I have no sickness, no known sickness."

"You said to me earlier that some people say that what you have is a curse," I say, "and you said that it's just the opposite, right?" "To begin with," says George, "I've had an incredible life, I would say *in-credible*. When I was a kid I used to stutter, stutter in such a way in which I couldn't speak out. In order for me to say some things I had to stomp on the floor," he says, with a loud stomp, "I was that way. I had brothers and sisters and everybody who lived a life more or less normal, for me, you know, everybody made fun of me. But I never held back, to me it was, well, one of those things in life and, what I did is, read. I read and read and read and read. In school I was number one. I did no sports. The only sport I did was swimming because I didn't have to talk. So when it came that after grammar school I had to graduate, and there was a way of doing things in Cuba at the time that all the families gather in the classroom and then there was an examiner and they would start asking you questions to see the quantity of what you have learned. At that time I was learning arts: painting, drawing, making things with clay, and the director of that academy told me 'George you've got to be a part of that tribunal' or whatever, and I couldn't answer the questions. So the director of the school told me that if anyone asks a question which no one can answer I'm gonna have to ask you. So they sat me in the very center of the classroom and that was the trigger that I needed. So then came one question that no one could answer, and they said answer it, and I answered it, but how? I couldn't, I tried but I couldn't and a teacher said 'Sing it for me' so I did, and I answered it. There was no speech therapy, there was nothing. So I came to think that

since I can't sing all the time, the signal that my brain sends to crash it through must be a *rhythm*, singing gives you *time and rhythm*. So I thought I had to devise something, so I thought that instead of concentrating on what I'm gonna *say*, instead I'm gonna concentrate on *pronunciation*, how to *pronounce* the words. And I started doing it, pronunciation and I got better, very slowly. When people around me heard me talking they called me the diplomat because I spoke so slow and so well pronounced that I sounded like a diplomat. I *knew* so much because of so much I had read, right, so talking slowly with good pronunciation, ever so slowly, bit by bit, it's gone. Once you start then it's something that have to do.

I was living in New York when I was young," says George, "and this place I used to work, the owner, he used to stutter, and he saw me, that when I spoke to everybody I didn't stutter, but when I talked to him I did, and he says 'Hey George, you're making fun of me,' and I said 'No I'm not, why?' and he said 'Cause you talk to everybody just perfectly all right and then when you talk to me you go [George imitates himself trying to get a word out]. I said, 'You want me to tell you something. I used to stutter, you've got to *work* on it,' and he said, 'You know, I didn't used to stutter but I was flying one of those Flying Fortresses [a World War II bomber] and it got shot down and I had to jump and every since I've had this stutter.' So there we were, and he realized what I said, and he tried it. This is the system that I devised for myself worked. Of course one thing in my life is I don't need to go about, this thing I'm doing to you now is *confession*, I'm giving you my life."

“At the time that Richard (33) was born,” says George, “the mongoloid was a *curse*. It was hide it, hide it, hide it, that guy’s watching you, hide it, hide it, hide it so nobody knows. No way! This is my son just as well as the other one, and just as well I’m gonna treat him. No special things, I’m gonna treat him just like the other one I brought up.¹ That is when I realized, I took Richard when he was a little baby to the Kennedy Foundation in New York. It was just starting up because Kennedy had a sister that was mentally retarded, and I took him over there, believing at the time that they were gonna give me an idea, a hint, or whatever, concerning Richard, the way I should treat him, and then I realized, I made up my mind to bring it up just like a real human being, nothing restricted. His tongue used to stick right out, about this much. So I said ‘Well, I ain’t gonna hide it. I’m gonna take him everywhere I go. If anybody used to glance at me sideways, you know look at me like this because nobody saw these kids, people used to hide em, if I noticed I’d go to them and say ‘Excuse me, do me a favor. I *want* you to look at him, right here, *look at HIM. Please, look at him.* Look into his face.’² In school, remember, books, books all the time since I was a child; books in my house. We sent Richard to a school run by this psychologist run by a psychologist or psychiatrist, I dunno, and this fellow came over and saw Richard reading, and this fellow, very *adamant* said ‘What is Richard doing?’ and I said ‘Richard is *reading*.’ ‘Don’t fool yourself,’ he

¹ Note here George’s relation to the public secret that exists around such situations. His immediate response of “No way!” does not, as it may appear, display a need to expose the secret so as to confront society with guilt. Rather, his response moves the public secret to a higher level—from a level on which what is known but not talked about is a “family secret” to a level on which what is known but not talked about is a secret of the erotic nature of human relations in general.

² What George refuses to hide is the very humanity of Richard, the transgressive nature of his very countenance, his interiorized *logos*, and the way they both pull us to think about humanity, Eros and relationships in general. George is a philosopher at heart and, as we shall see, one with a great deal to say and/or show regarding the above subjects. He and Richard are, as the psychiatrist might have them in Symbol, not the father and son of the crucifixion. They are rather, in their very countenance and attitude,

said, ‘these kids cannot read; they learn by rote.’ ‘They cannot read?’ I say, ‘No,’ ‘Okay take whatever he is reading,’ so he takes the book, looks at it and gives it back to Richard, ‘Okay Richard,’ I said, ‘read it,’ and this guy says ‘OHHHH, [the sound of sacrifice] that’s not *possible*, he’s *reading*.’ He’s always had problems with pronouncing words, but his spelling is better than his brother who is a lawyer. Richard never sits and does nothing. The minute he sits he’s looking around for something to read. Always, always, always his mind’s never blank. He’s always doing something. That’s the way I brought up Richard. We took him everywhere.”

“Have you learned a lot from Richard and Cecelia?” I ask. “Oh yes yes yes yes yes,” says George. “In what ways?” I ask. “With Richard I learned that people, they have

a tendency to put you in a niche or a pigeonhole and they, humanity, you have to accept it.

You are not gonna go in the world teaching them the way they have to behave. You have to accept it and try to help. If they come for help, I will gladly counsel them, but otherwise I’m not gonna give a sermon on what ought to be done, what I have learned from Richard. Now what is accepted is that these kids, of course there’s so many *degrees* at which they can learn, his mind works on a different wave length than ours. We put him in a niche of mentally retarded and they say ‘Well, there you go, whaddaya gonna do?’ But what this lacks is that *we* do not have the knowledge to communicate with them and how, then, can I come to this conclusion? Well, I come to this conclusion

spirits of Socrates—the older of whom, in his dying breath, depends on the other to see that this spirit may live on in others of his kind.

simply by saying ‘You know what electricity is? The only time when you may see electricity is when you might be in a thunderstorm, right?’¹ Otherwise electricity or sound, or whatever, there are so many things that you cannot see, wavelengths, you cannot hear, a dog will hear something you do not hear and so forth.² So they, to me, are special in this concept, that they are *special*.

Richard is not mentally retarded from so many reasons. Now, how you reach them, that is

the main question. There has to be a way to reach them. For instance, one of the things that has come to me, the two most important statements in language: yes, and no. For ‘no’

you can go like this [shaking his head] or like this with your finger [wagging it back and forth], or use your mouth. We have three ways of expressing this, we know the concept, but Richard does [holding his finger up to indicate ‘one’ and then bending it at the knuckle]. Now, his memory is out of this world. Anywhere I go, I know so many different people and so many different situations, I forget names. Richard always

¹ George does not rely on relationship or any other chemical metaphors as do all of those who take he, Richard and Cecelia symbolically. All of his descriptions in fact resist this very common, nay *expected*, form of description. Notice how, instead, he resorts to the metaphorical realm of electricity, a realm through which we “communicate,” but which we do not understand. Note also how, immediately and still within this realm of invisibility and knowledge, he also includes sound. Seeing the ways Richard works the room of the Alzheimer’s daycare center one can see the truth in George’s sentiment—that there is communication which is possible, but through some medium like electricity and sound which we cannot see but, watching Richard, we know is there. In saying this, I argue, George points to the very materialist Stoic logocentric metaphysics which I have addressed in detail above.

² Not at all unlike Kafka, and *maybe*, according Benjamin’s interpretation, too much like Kafka, George, Gabriel, Carmen and others rely on and think through animals. Here we see once again a strange tendency, so beautifully spelled out by Michael Taussig in his *Mimesis and Alterity*, for the mimetic and/or understandings of other metaphysical orientations—too often construed, dismissed, or abused as “primitive”—to be construed as animal-like, and not too human. Perhaps the true genius of George is how he focuses not on the dismissal or abuse of other understandings of other metaphysical orientations, but rather focuses on their *misuse* in terms of the Symbol.

remembers, so I feel at ease, because he's with me. Those are the things that he has, all those experiences, all these experiences are what is to me rewarding."

"Have you read books on Down's Syndrome?" I ask. "You name it, I've read it," says George. "What do you think of them?" I ask. "Obsolete," says George, "obsolete. I never went to college or anything, but every time I tackle something there's a technique that I have devised, that's not given to me by anybody, or by any book, but simply because of the *necessity*. I did this with my studies, I did it with Richard, and with Cecelia same thing."¹

At last count George and his family were participating in five separate studies regarding Alzheimer's disease, and Cecelia was on her third drug trial. George was always willing to help with any study he could. The reason for the interest in George's family was not in their willingness to participate, but in the fact that in this family one found a genetic arrangement which is both related to Down's syndrome and Alzheimer's disease. In particular, this certain arrangement was strongly correlated with the early onset of this disease.

Despite his deep involvement, and almost reverential regard toward the University Hospital clinic, George's case remained quite different from most. As a

¹ Note again how his own "disability," his son's, and his wife's are, as I said above, all run together in a way which, as Harwood might say, "broadens the subject through being brief."

caregiver George had for decades resisted the social pressures of the (I)nc. while allowing the symbolic integration of medical science to take place. MRI's, CT's, blood work, psycho-social testing and all that were fine and good. He firmly believed his involvement was the right thing to do, and it was, but when it came to the social aspects, positions, and approaches he became a rebel, and remained one. Labels, situations, and systems of regard such as retarded or demented he resisted in the same way he resisted his own identity as a stutterer, by devising his own techniques.

One cannot help but be a bit suspicious of this as well. The very idea that someone like George, so unschooled in the complexities of aid and its symbolic integration, should really be given credit when he calls all the work on Down's syndrome "obsolete" may seem too generous and/or a bit naive on my part. I give him credit because George and I share a distrust of aid and symbolic integration; we share a view of such aid as a gift which we would rather not receive and whose debt we would not incur. Neither of us were really offered it, as neither of us ever made it known we wanted or needed it. The price is forever too high really, and the very thought scares me as I've seen the effects of this debt time and time again. I really don't feel right, I don't feel honest, wanting it. I feel that if George or I had ever been "gifted" in such a way, we never would have met as we did and, like my encounter with a water priest (which I will soon tell of), I would have never seen myself in him. Listening to George it was as if time and space, culture and language had all collapsed and we were one there, unable to speak but knowing. OHHHH have I been there, countless times, a lifetime if not more, in that space with him, alone—watching others talk, blurting out this and that, *saying it*,

speaking it, just like that , simply, naively, starting sentences with any and every sound, quick come-backs, what must that be like, to just be able to do that, to *never* be stuck in that space, losing air, sputtering, eyes rolling back as if possessed— funny as hell, literally speaking. It, no, humanity, creates a violence, I am sure, and envy, a need to be able to move things with words, a *controlled explosion* , of beauty, of a cry. I can't help but smile thinking of it, stomping out words like a horse (mind the animals!) and I, like George, encourage you to, *here*, as well. Why not a whinny, why not a bray!

But then there's reading, and technique, writing and gestures (like Richards bending finger) learned habits (like George's annunciation), used when at all possible, *not to hide it*, (there's nothing to hide and I *won't*, I will *never* shut up!) but to sublimate it, to use it, like melancholia, to live through it, to make it the most valuable part of oneself, ones most valuable resource come what may, to lyrically and scientifically destroy that language, that system of aid which seeks to rob one of its mystery, while offering nothing but pity to mankind in return. A message to Horkheimer and Adorno: the *real* test subject, the *real victim* of the Enlightenment is he or she who is *taken* representationally, and the *real subject*, of the miracle and love, is he or she who has faced the humiliation of mankind and, in gesture and otherwise, like the animals we are, emerged beyond it.

New Center, Alz Periphery

I first came to the New Center my second week in Miami on the invitation of a social worker there. From that day on I took part in their activities, coming and going as

I pleased. Among these activities was its weekly meeting, called staffing, in which the whole staff of social workers, M.D.'s and other professionals discussed cases, determined the diagnosis, and decided on what to do. No one was sure what to make of me there at first; 'what was my project, what data was I collecting?' After a few months no one seemed to notice or care much. The chief and staff neurologist Dandas, although welcoming and ever willing to answer questions about neurology, lend books from his office and so on, couldn't help but regard me with a bit of suspicion. I remember, though now I roll my eyes thinking about it, sitting in his office the second week I was there and asking him if he thought it would be theoretically possible to reproduce the symptoms of Alzheimer's disease in a social way. I remember him looking at me curiously and then referring me to psychiatry where I would find M.D's who might be more receptive to such ideas.

I approached the New Center in a very critical and negative fashion from day one. Listening to the protocol summaries, one page "life histories" and loose assumptions of things social (my "specialization") rubbed me the wrong way. Most of what they did I saw as symbolic integration into a system, an ideology, which didn't seem to respect the rights of people like those I was dealing with every day at the daycare center and elsewhere, nor to respect any reason outside of this system. Everything always seemed to be out of necessity, something real bad was always about to happen and it had to be nipped in the bud. Take the car keys, change the bank accounts (it was not uncommon for the control of huge sums of money to be on the line), 24 hour supervision, and

always, always take the word of the caregiver as the gospel truth, rarely, if ever, to be questioned.

There was also plenty of grist for my critical mill when it came to the physical, medical and “cognitive,” psychological sides to the diagnosis itself. Nothing here, it seemed, was ever for sure, ever as definite as I thought it should be. Learning where to interject with a “but” or a “but what if” in staffing was something I learned to do gradually, strategically offering a reason, now and then, outside of the rules, which was, from the start to my surprise, often carefully attended to and appreciated. Early on, however, I just kept it pent up for the most part, scribbling away in my journals littered with private exclamation points.

One time, I remember, we were discussing a patient who was said to be verbally abusive. At this point the psychiatrist perked up, seeing a necessity in the making which was to become his responsibility. As the discussion went on building this problem I interjected asking what “verbally abusive” meant. Odd looks were upon me. Verbally abusive, that’s what the caregiver said, abuse, which must be nipped in the bud, of a verbal form, no less painful than blows to the head. But details, I ask. Is he telling her to leave him alone and swearing at her when she doesn’t? Is he complaining more? Is he accusing her of something? Just what exactly *is* verbal abuse *in this particular case*? They seemed to find this question amusing, and I felt a real, banal sense of evil in their smiles. The answer was that it’s something to be nipped in the bud, with drugs— next case.

Staffing is a embattled borderland, a frontier, where Pietism meets the Alz people. The social workers check them, admit them and, if and when they are medically certified, allow them to immigrate and to continue the process of integration. The social worker begins by reading aloud the summary of her protocol and its recommendations. Then Dandas reads his own summary aloud, sometimes making comments on odd things he'd noticed, sometimes making jokes and giving observations and impressions of the patients, which others in the room would follow up on. 'We should be ashamed of ourselves acting this way' was the feeling, but we all knew that it lightened the tension of this symbolic inquisition which we needed to carry out. If there were MRI or CAT scan films, they would be hung up on the lightboard by Dandas and studied, he making verbal observations. When I first started coming to staffing only the M.D.'s and Ph.D.'s present would get out of their seats and look at the images. After I started doing it, studying anatomy and the reading of MRI images and making my own observations, many of which were wrong but became increasingly exact over a years time, I noticed that the social workers and the nurses started getting up and joining in. After looking at the films the psychiatrist would read, making recommendations for medication changes if necessary, followed by the neuropsychologist (Mom's "David," or "Dr. Bernstein") who would take the most time going through score after score constituting a fully quantified mind. It was here, in consultation with Dandas, that it would be decided if the patient was "demented" or not and, if so, to what extent.

If demented, the question turns to ‘why?’ There are dozens of things that can bring about such a state and the point of all the medical and psych tests is to ferret out and exclude each one of them. When every other possible diagnostic category within (this) reason has been excluded, in a process called “diagnosis of exclusion,” we could call it “Probable Alzheimer’s Disease”—it being *probable* due to the fact that this disease can only be definitely determined at the microscopic level of neurons which, due to the risks involved in brain biopsy, can only be obtained post mortem. About ninety percent of cases, I would say, would end up with this “probable” diagnosis, at which time medications are prescribed to pacify if delusional, hard to control, and so on or, as is usually the case, to lift if depressed.

The New Center was always an open door to me. I would come in, get some coffee, talk with people, have lunch with them, borrow books, use their databases and on-line services, make photocopies, look through any of their files and study their MRI and CT images. As time developed I turned away from my earlier interest and contacts with the social workers and more towards learning the neurological and psychiatric sides of the clinic. Following through on one after another case studies, medical dictionary in hand, I came to not only feel at home in the neurological charts, but to respect their content more, to feel a fascination in this self instruction and the many ideas it began to suggest. With the social workers I was inevitably frustrated. Healing, that which I wanted most for these people, had become caregiver satisfaction or, rather the community’s satisfaction that the caregiver is satisfied with the community/the word. They talked the social, and manipulated it without a care of thinking through their words

(the word) and their community. I came to understand the wisdom, the deferral, in saying “I can’t say” and I came to critically reconsider any and all knowledge of the social aspects of healing and the all too human side of care, peace and understanding (and the heavenly rewards) which it offered the Alz people in return for their submission.

The Morgue

Thursday mornings, and other days now and then, meant a trip to the morgue. Sporting my best tie, white shirt, lab coat and ID badge I would make my way through the back halls of the hospital, finally coming to an area next to the loading docks, where hospital workers milled about, smoking cigarettes. Near the end of this hallway was a door with a small sign, “Morgue” and below it “Access Restricted to Authorized Personnel Only.” Through the door one comes into a small hallway with several other doors, all closed, the smell of Formalin (formaldehyde) in the air. Around the corner and through the double doors one enters a room of metal fixtures, running water and plastic bins filled with chemicals and organs in chemicals mixed with water. By 9:30 the medical residents show up, by which time I’ve usually looked over the case histories, snapped on a pair of latex gloves, taken out a few brains from their buckets and looked them over. Although I’ve cut the brains on a few occasions the pathologist, Dr. Mary Cassini, 52, usually asks the residents to do it, I suspect because most of them would rather not.

This is where the last stage of the diagnosis of Alzheimer’s disease begins. Upon death the body is brought to the morgue as soon as possible. Often we end up sitting

around the morgue office listening to stories of the morgue and hospital, some wild and others puzzling, while Lloyd, one of the morgue attendants, continually asks people who come through the door if they'd like to be the next body so we can get on with the work. When the body arrived we would put on the plastic suits and get to work removing the brain from the skull. Often a full autopsy was not performed on these elderly persons, just the removal of the brain, which would then be placed in Formalin and "fixed" for two weeks before cutting and inspection.

After studying anatomy from textbooks I came to find the braincutting and full autopsies most fascinating. Always considering myself to be a bit squeamish I really didn't know how I would react when I first started coming to the morgue. There are certain images of bodies which do stick with one, and continue to make me feel odd now as I write about my experience from a distance. At the time I had no distance and the more time I spent in the clinics with the M.D.'s in diagnosis, in the morgue and in the medical library, the more I was drawn to know more. After I started visiting the morgue the anatomy and physiology of the brain came to take on whole new senses in my imagination, came to inspire idea after idea which I continually struggled to sort out. It was in this instruction, which remained mysterious to me, as it should, that I found what I felt was a way out of the dilemmas of the clinic and toward a discovery of the cause of this disease and its problems.

Like my time in the clinic, I also approached the anatomical theater of the morgue with a critical attitude, especially the brain cutting. Inevitably, by 9:45, a group of

neuropsychology students would come in with their professor and he would point with a pencil to the slices, which the residents had laid out in order on the cutting boards, quizzing the students in neuroanatomy. Along with his pointing came a lecture on location, 'if this is damaged, what happens, if that is atrophic, then what?' You see, this or that faculty is *located there*. I much preferred being with the pathologist at the other end of the table, 'feel this, does that feel soft to you?' Sometimes she'd pick up a slice and smell it, while the Neuropsych students and medical residents would pretend not to notice, but think her very strange. If it's not fixed as well as it should be it would smell, and this would make a difference in what you're looking at. She would often begin, before a brain was cut, by asking us what was remarkable with this or that brain. For so long I held back, answering only to myself, while the residents squirmed, saying nothing, as usual. Before long, I found many of my silent answers being right, and would once in a while say them aloud; edetic, jaundice, atrophic here or there, and so on. I would often be asked questions about Alzheimer's pathology, or maybe quizzed, to which I could often give a version of "I can't say" in knowing and familiar regard. I often felt, like all who specialize in this or that I suppose, that the 'Probable Alzheimer's' brains were not given as much attention as they should have been. Four out of five cases in these brain cuttings were strokes and brain tumors, many involved AIDS and its related problems (Dr. Cassini's specialty) and a good number were of children. In the latter, as well as many other odd cases, one could smell the legal fixing taking place with each mark of the pencil on the autopsy report.

Some people wore masks the whole time of the brain cutting, while others, including myself, never did. Those who wore the masks in such cases were always residents who quite clearly did not want to be there. Some would say they don't like seeing the failure of medicine, others that they like to focus on healing and dealing with living people. I couldn't help but feel they were in the wrong trade. In pathology the final say is said, but those who fear the word, which includes a great many physicians, fear the morgue. I remember one time when we were looking at changes in a brain affected by AIDS Cassini dropped her pencil in a small pool of residue blood mixed with Formalin next to a slice. Grabbing a paper towel she wiped it off quickly, "AIDS pencil," she said, and went on writing. As she finished she looked up at the Neuropsych students watching her, 'No, *really*,' she says, "HIV can't live long outside of the body's environment and, besides, the Formalin would have taken care of it anyway.' In the Anatomical Theater of Leyden, one of the great anatomical theaters of 16th century medicine, devoted to mysterious instruction, one found animal skeletons decorating the walls, human skeletons holding banners reminding of the transience and vanity of earthly life, and two skeletons upright on each side of a tree, representing Adam and Eve. Over the door to this theater was an inscription which read "God is here too."

Medical Library

Wandering through the hospital grounds, past the bookstore, the McDonald's, the ear and eye institute and the thank you statue honoring organ donors ("In their last hours they gave a lifetime") one comes to the steps of a beautiful building surrounded by trees. From somewhere, beside, behind or from this building itself the religious music of bells

chimed various tunes. Though I was usually moving in haste, as all in Miami are required to do under the penalty of law, I was always reminded of both a funeral and a wedding as I entered the chiming doorways of this building. Over the door here, in the form of music, one was also told that “God is here too.”

But what a place for God. Where was he to be found among the thousands and thousands of medical journals and books. The bells could have equally chimed “Enter not ye who seeketh knowledge of God here.” There is nothing apparent here but quick in and out pragmatism and careerism. Those who linger do so for the utilitarian ends of sleep or passing the next test. I came like Nietzsche’s madman in the town square, my lantern of enlightenment shining in the darkness, with a strange announcement. I’m looking for the cause, or the path to the cause of this “disease” but where has it gone? I can’t see through the darkness of God, a blind stumbling in endless deferral. Here are journals devoted to so many topics one scarcely knows where to begin but, within each entry, are referrals to other journals and other entries. Being neither a professional neurologist, pathologist, histologist, and so on I did not do what most M.D.’s do, that is, read two or three journals in my specialty. I approached this reserve of knowledge or, rather, of deferral, with an antiquated enthusiasm, supplementing my knowledge of anatomy and physiology as I delved ever deeper into the most specialized realms of research on this disease, and research in other areas which I found related to it. A foolish pursuit for which I was unprepared? Well, this would seem right *if* I hadn’t learned the Alz language, *if* I hadn’t learned the logic, the *feel* of “I can’t say.” What could I possibly stand to gain? But that was the question; I didn’t know. As I went on, month

after month, visit after visit, trying this and that out, testing this and that mentally and verbally in the clinics, the morgue, the daycare center, the support groups and elsewhere, I came to feel an incredible wonder and a certain confidence as I saw things fit together. This was a gift of time, of the God of this strange chapel filled with ideas, a spirit to which I had sacrificed and which I had consumed and wasted luxuriously and, in the eyes of the M.D.'s, unashamedly. Bobby B. spoke of time, and scarcity. Some researchers, says Bobby, have an understanding of the pieces, some bigger, some smaller than others. I certainly had collected more pieces than Bobby, and maybe as many as Dandas by the end, I can't *se*, but the key, as I always saw it, had to do with knowing what the picture of the puzzle one was piecing together *looked* like. To get this picture one had to assemble as many aspects as one could of this "pathology" and reduce them, find their common, *qualitative*, denominator. The idea that I could do this was, and is, no more delusional than my subject. I came to see that these Alz people have a picture of what is wrong with them, that a key lay in their lives like a story, sunken in. We better approach the solution, this picture/key in a way which many healers around the world bring us to approach affliction; in seeking an image, in obtaining an image (or a system of images of the body), and following its mysterious instruction to a point which is no more and no less delusional than our subject. This is, on one level, what Harwood means by enlightenment and is, on another, a lesson to be drawn from Nietzsche's madman.

Chury and the Pietist Ministry of Culture

“What were your first experiences with Alzheimer’s disease and people with dementia?” I ask Chury, 44, the New Center’s newest social worker. “I was coming from the field of addictions in which you *confront* people,” says Chury, beginning to laugh at herself, “and I started confronting Alzheimer’s patients and what was happening was, instead of distracting them or redirecting them to do something else I was *reinforcing* their behavior, and I didn’t understand so, little by little, I started learning. But that had been my *training*.” We both laugh. “Were you trying to do reality therapy,” I ask, still laughing, “like ‘you are here, and today is Tuesday’ and that?” “Yeah,” says Chury, rolling her eyes, “so I went to several seminars on Alzheimer’s and started reading stuff about it and little by little learning. But, some of those things you see in those programs are more geared towards the American community, even the activities. For example, there was an activity when I was in Hialeah housing, that they wanted to bring into Hialeah, and it was with clowns. Well, little did they know that the Hispanics are very proud in many ways and of course *no Hispanic lady* is gonna dress-up like a clown. She will sit down for hours taking care of a patient, *hugging* them, you know, being very *nice* to them, but she’s not gonna dress-up, they’re saying ‘I’m not gonna dress-up and look like a fool,’ and that’s a program they wanted to bring in. It’s something that Americans are not very conscientious of, you know, it’s something nice, it’s something *fun*, but for a Hispanic lady, as a volunteer, that is, well, *forget* it. She thinks you’re making her look like a fool.”

“What were the big differences between the English speaking and the Spanish speaking people with Alzheimer’s you worked with?” I ask. “With the Hispanics,” says

Chury, “you can use a lot of *touch*. It is even easier for us to express things without saying them because we use the hands so much. So sometimes when the verbal communication doesn’t work it is much easier to communicate with an Hispanic elderly. An Hispanic elderly who might have problems understanding words, who might have lost the sense of many things, of what is a chair, or where they’re going, just with the expression of your hands, your face, just by touching them, when they get very agitated, you know, I could *hug* them and could do a lot of, you know, *touching therapy* which would relax them. For someone who’s not *used to* this, and many of the English speaking patients were not that used to this, it would be as if I was intruding myself in their space and, instead of helping and soothing them, they would become maybe more agitated. Not so much with the Blacks; I found that with Afro Americans it’s more like with Hispanics.”

“Did you find that, in dealing with the Hispanics, were they different from the English speakers in their particularly odd behaviors?” I ask, “For instance I’ve noticed in the daycare center a lot of the Hispanics may be concerned with romance and love, and the Anglos are generally not so much.” “Yeah,” says Chury, “I think the difference is, again, that we are more *expressive*. That its very normal for the compliments going both ways. For example, you don’t see here in the United States, like in Hispanic countries, she’s gonna get a lot of compliments from the men, they’ll say things to her, and in some countries, like Spain, they’re *very creative*, and sometimes it can become almost like a *poetry*, you know. The beautiful things that they say to a lady, complimenting her on her eyes, or the way she walks, and the *women also*, not so *outwardly* as the men, but we *do*,

you know, this complimenting and telling people you're looking so *nice* and you're looking so *good* and 'wow, that tie looks beautiful on you,' is very much a *cultural thing*. I cannot say maybe in Mexico and other countries, but *in Spain*, it is, in Cuba also. It is very common for us in Cuba to even use affectionate words '*mi amorcito ven aca*' which means 'my love come over here.' It doesn't mean that this person is your *love*, it means that we *use* those words. Women do this but men also do it, but women do it more. In Cuba we use those words a lot, and romance is something we enjoy a lot. Hispanic women loved *novelas* [Spanish soap operas] from *way way before*, but in the United States, soap operas, *now* is when they're *really* becoming *popular*." I nod, wondering where she *gets* all this. "But in Cuba, and in other Hispanic countries" says Chury, "this romance thing is something that is part of our *culture*, maybe more *openly* when some of the inhibitions are not there, in a patient. I mean you will find ladies, I mean women which you would call *ladies*, who have never used foul language, who have never done anything inappropriate, who've always followed what the social rules say you should do and, all of the sudden, they are using the foulest words, they're taking off their clothes in front of people and they're being aggressive."

"Why do you think they *change* that way," I ask. "I think it's whatever controls your inhibitions is gone," says Chury, "whatever controls your ability to differentiate between the toilet and the hand basin. I've seen them wash their face in the toilet, and maybe that area of the brain is affected."

“How do caregivers understand the disease?” I ask, “Do they want to know a lot about it, or do they trust you here in the New Center and they don’t want to know details? Are they interesting in *knowing* a lot about the brain and these things?” “I think many caregivers are interested in learning about how to *deal* with the patient;” says Chury, “how to be able to *cope* with the disease. They’re not that interested, you know, in the disease itself. As a matter of fact it’s something that scares them a little bit. It’s the theory ‘the less that I know, the better I will be.’ But they are interested in how to cope and to deal with this individual so they can keep him at home for a long time.”

“When you say they’re scared of it,” I say, “do you mean that knowing about it terrifies them?” “Yeah, right” “Why? How?” I ask, “Tell me more about that.” “Well,” says Chury, “if you have a person that you love, okay, there are diseases, for example, it’s not that terrifying to know that a person has a problem with their appendix, their stomach or something, but something with the *brain*, knowing that that person may stop being the person that you love, that the person’s brain is *atrophied*, it’s going to be *deteriorated*, it’s *terrifying*, something which they don’t want to *know*.” “Why do you think that’s particularly terrifying?” I ask. “They’re scared of mental illness. They’re scared of losing that person. In many ways, in their mind, it’s comparing the person with retardation and that’s something they don’t want to deal with. They don’t want to deal with the real facts of it. It’s like when someone is going to give you a *soup*, made up of things you don’t like that much, you don’t want to know about the ingredients because you might not, you know, eat it. I don’t think that’s even *cultural*. Nobody wants the person that they love to be demented. Even that *word* scares them. When I was in the

daycare I had to be very careful not to use the word ‘*loco*,’ which it is *not*, but I didn’t even use the word *dementia* because “*dementia*” in the old time was often used to describe “crazy” and psychosis, and they don’t *like* that word. I would just say ‘Your family member, your spouse, your mother, has a big problem with *memory*, has a lot of *memory difficulties*, you know, and I would explain, but very broadly, what it was. But that word *dementia*, they don’t *like* it. To say ‘*memory*,’ *memory* doesn’t scare them.’”

“Does the word “*depression*” scare them?” I ask. “No,” says Chury, “they can talk about depression and anything that has to do with *feelings* is fine. I can tell somebody that they have a psychological problem, but with “psychiatric” you have to be careful because to people that means “crazy” and a “*crazy person*” can become *uncontrollable* and then they cannot keep that loved person with them, you know, it brings in a lot of *fears*.”

“Is this the reason then, you think, that they’re scared of talking about insanity, because they think that they’ll lose the person?” “Yeah,” says Chury, “it has to do with ‘insanity.’ When you take it away they’re more *open*. They will start talking about the person’s *feelings*, and how they *behave*. They don’t mind talking about if they become aggressive, or if they become childlike, or inappropriate in their behavior, as long as you take out ‘insanity.’”

Chury feels strongly that daycare is very good for those with Alzheimer’s. She feels that being with the family is absolutely the best place for these people, especially

the Hispanics. There is something excessive in her thinking about “Hispanic culture” which is here and elsewhere strikingly apparent. Indeed sometimes it seemed that everything in Alzheimer’s disease could be made by her to exist in this realm. It is almost as if the disease was itself a disease of Hispanic culture, a disease which spoke English and had something vaguely to do with American imperialism and the inability to achieve a place for *Hispanidad*.

“I have a friend,” says Chury, “and you know I always have this in my mind. Her husband has Alzheimer’s. He’s been in a fetal position for over three years. He has that lift and she takes him to the family dinner every night, in the lift. She takes him in the lift to the living room. He’s there with his family. He doesn’t communicate, but I think he feels the love of the people around him. It is very hard when a human being is deprived of that love.”

On the subject of *santeria* Chury says: “I think a lot of the Hispanics, their relationship to *santeria* has a lot to do with superstition. People go to a *santero* like people go to a psychic. People want to *know* what’s going to happen. People don’t like to live not knowing what’s going to happen tomorrow. They want to be *ahead*, they want to know *everything*. So the *santeros* tell them what’s going to happen.” “But when they come to the *medical* doctor they don’t *want to* know their future,” I say. “No,” says Chury, “because a medical doctor’s gonna tell them about things they don’t *like*. A medical doctor talks about veins and hearts and organs. How many people want to know that? Also the medical doctor, I think a lot of people feel that, you know the expression

that the doctors somehow think they're God. Well, in many ways they *do* have a lot of *control*, or people *allow them*, because of their *knowledge*, to have a lot of control. The witch doctor, you can take him or leave him, but you *need* the medical doctor, and then you don't want him. You want him to help you, yet you don't want to give him that much control and also you don't *know* so much about those things. When you *know* them those things are more familiar, when you don't those are things that are scary."

"Do you think it might be better then, that people know more about the disease?" I ask, "Then they would have more power." "I think they should know more about the disease," says Chury, "but the people who *teach them* should know more about their culture; teach them about the disease in a way which is not *threatening*. One thing is the word "dementia" is a no-no. It is the word that is written when you send them a summary. It is the word that a doctor will use. It is the word that is used in the hospital. The word is scary. In the language of this person you're telling them that their loved one is *crazy*."

"Have you heard people ask the question of whether this condition is some sort of punishment or the result of something the person has done," I ask. "I was gonna tell you that Hispanics sometimes don't like too much the 'why?' question," says Chury, "but this is *one* area where the 'why?' question is very widely used."

Bobby B., Alz Technician

“I’m one of the few locals,” says Bobby, “born and raised in Miami. I went to school here at the University of Miami, got a bachelor’s degree in mathematics, a master’s degree in mathematics, and masters in electrical engineering which I actually did a dissertation based on work here at the New Center, on computer-assisted analysis of MRI images of the brain. That was in 1991, and I never really followed up on that. It’s one of the things I regret in some ways. I see it happening all over the place, a lot of good ideas getting stuck at the dissertation stage and people not going through with it. I guess people don’t have time, they have to *work* and make money and so forth, so it wasn’t a priority here. I’ve been here since 1984, going on thirteen years now. I came at about the same time as Akhil [Dr. Dandas]. Back then it wasn’t the New Center yet; it was a brain imaging center called the PET project, positron emission tomography. We had an old PET scanner that was of 1981 design. So after about five years, they keep outdating them, but Akhil did a lot of activation studies, of dementia cases, especially Alzheimer’s cases and published quite a few papers, and some chapters, and I worked analyzing that.”

“How did you choose math?” I ask Bobby. “Well, I kinda *liked* it. I didn’t like theoretical math but I like applied math, so my first job was actually doing underwater acoustics for a company that did Navy contract work. I came here through my work with computers. Here we started doing more clinical work, Akhil started collecting information about his patients, Neuropsych information, family history, drug information, mishaps, etc. For seven or eight years we’ve been concentrating on diagnostic issues, collaborating with other centers.”

“Do you and Dandas usually publish together then?” I ask. “Yeah,” says Bobby, we usually do.” “And what do you do and what does he do on a study, how is the work divided?” I ask. “Actually recently he’s been doing less actual writing and more supervision, maybe because his clinical load has increased *tremendously*. Actually, I see a tremendous increase. I’m not sure what to attribute it to. Medical science is more demanding than it used to be, they have less research time so others like me and Dylan and the others do more of the writing and actual research than in the past. Akhil *likes* to do research, but he... a lot of the *informal* type of research physicians, or other people, were doing in the past is just not available now. They just have less time available, so before these people were collaborating or actually doing research but now they have less free time. That type of informal research is now on the decline. I’m not sure how much time this center will have for research. We’d like to do more, and it’d been great if someone in Miami, the University of Miami, were doing genetic research, for example but things didn’t work out, people don’t cooperate.”

When Bobby says “medical science is more demanding than it used to be” what does he mean? The demands of which he speaks, but does not speak, which he says, but cannot say, are the demands of service, of the competition of care and the market of which social workers are brokers. More “demands” are being made by a population of healthcare consumers and those who make it their and everyone else’s business to care about this population and its approval. Sure, a paper on the subject of platelet factors among those with moderate and mild dementia could be significant to “Science” (of the

body) but medical “science” and its “necessities” as Bobby has come to know and resign himself to them, i.e. under the sway of Pietism, is much more concerned with what it calls the “quality” of care, but which is essentially the marketable *perception* of this “quality.” A study about how depressed Hispanics are (maybe tossing in some stuff about “Hispanic family values”) as compared with African Americans and Non-Hispanic Whites, is not only better in terms of the quality-of-care-perception, it is also quite cheap to undertake and easier to publish. In this game the Positivism of science itself is changed to the “-ism” of the positive *image*, so dear to those “-isms” of the Pietists and/or the state.

Essentially all positivism, by *any* definition, is a game of numbers. “Aren’t a lot on clinicians weak on statistics and math and rely on people who are good at it to help design their projects and interpret the data?” I ask, Bobby. “Yeah,” he says, “a lot of physicians know their limitations and, if they want to *publish*, they need to do some statistical work. There was a study from MRI and they only needed a t-test, very simple but they needed help on it.” How is this clinic, being private, different from non-private ones,” I ask. “Well,” says Bobby, “if we didn’t have private funding like we do and had money from the government or the state of Florida we probably wouldn’t have so many social workers. We’d have Dr. Dandas, maybe a psychiatrist, you’d probably have a nurse, and you may not have a social worker. You’d have a trimmed down staff. There are three full time social workers here, and one part time. Some of these places are funded by drug studies, that’s their main goal. They get probably a little bit less respect.”

Again the fact: a private clinic such as this needs more social workers. Why? To provide (the perception of) “quality care,” to be sure, but *also* because there is a strong relationship between the (I)nc. and *this* “science.” Bobby knows the game of the colonist well. Pietist science turns the “I” into the (I)nc. at the blink of an eye. Questions about ones own instruction in Science (of the body) are taken and answered as Pietist science (of the spirit).

“Have you learned a lot about biology and physiology the thirteen years you’ve been here?” I ask. “Yeah,” says Bobby, “I have learned something about the brain I guess, not as much as I would *like* to learn, this and that, about the diagnosis of dementia. I guess I’ve kinda applied it to the people I know personally like family members, and uh, I have a grandfather who died at about the age of 71 and at the time he died I didn’t realize that he had dementia but now, looking back, I’d say he probably did have dementia for about one year.” “Is that what he died of?” I ask. “Well,” says Bobby, “he had some *medical* problems too, something like arterio-sclerosis. He became very apathetic near the end, and very passive, and he didn’t do anything, just sit and watch TV, not remember what was going on. I guess we attributed that to medical problems but I guess if he were living *today*, you’d see a difference in my education, in many people’s education, they’d receive treatment or at least an opinion I guess.”

Could it be, despite the power of Pietism in this clinic, that Bobby and others are using their own experience (as Pietism forces them to examine and interpret it in terms of the Symbol) in a *lyrical* fashion to in some way inspire their own Alz scientific

investigations. Could this be a form of unnoticed resistance to the (I)nc. within the clinic?

“How do you guys come up with your ideas for research, or where do the ideas come from?” I ask. “I guess most of them come from ideas that have already been out there for a while,” says Bobby, “risk factors for Alzheimer’s disease, and when a *new* risk factor comes along we always collect this information. Other work like, for example, the study we’re doing about occupation, we have a good data set of Alzheimer’s patients and we have a matched group of people from the epidemiology study that came from a publication last year. Actually there was something published a year before that but I didn’t take it seriously and then another study came out and I thought maybe there was something to it, we should investigate.”

“Epidemiology is one of the best tools of a quality care publicity package, the best form of Pietist evangelism,” writes Gabriel. “Get them talking and then talking *to us*.” But what of how the public perceives scientific work? This seems *so* important to “the cause.”

“How would you compare the science of medical science to the sciences of mathematics and engineering which you’re trained in?” I ask. “Well, I would say that medical science depends a lot on experience, I guess, but I suppose applied mathematics does too... I would say the doctors I’ve met or worked with, either at a professional level or a personal level, I would say are usually very bright, right, pretty logical. Sometimes I

might question something that might, say, that might be mythology. In math we're more prone to say 'wait where's the proof, where's the study that shows it.'" "What would be an example of that?" I ask. "An example would be like a doctor, say I called them up and say my kid has hives and brought the kid in and they say there's nothing they could do... Well, I guess that's not a good example. I guess doctors do have a lot of *rules* probably. Most of the decisions they make are based on well-established rules. I have friends who say it's tougher being a car mechanic than being a doctor because the human body doesn't change. Of course some of the tools and medicines change, but a car, they change *completely* from one year to the next, and they're are different models too. So I'd say its more difficult to be a car mechanic than to be a doctor. In a sense I guess he's right, doctors adhere to a very small set of *rules* I guess." "I guess there's a lot of responsibility or answerability on the part of doctors though wouldn't you say?" I say. "Yeah, right," says Bobby, "but usually they work with a small set of rules, you know in their experience they've seen some unusual cases but I suppose someone like you, say in dementia cases, in six months could be trained to agree with them over ninety percent of the time."

I brooch the subject of politics and colonialism more directly, knowing full well that quality care is too nervous a system to be approached thus.

"What do you think about the effectiveness of the social workers and this idea that the real *suffering* of the disease is on the caregiver and the idea that studies should be oriented towards the caregiver," I ask, "because a lot of the studies you people here are

now doing are oriented in such a way?” “Well, we’re doing *more* of that,” says Bobby, “I mean we’ve always had social workers who’ve interacted a lot with the caregivers, but I’d say the focus is still primarily on the patients because we’re primarily a *diagnostic* center and a lot of the effort is in diagnosing the patient. But, I mean, the patients for the most part come with a caregiver so they’re kind of inseparable.”

Is there a language of “the people,” and who am I to suggest I understand more about the class struggle among them than they themselves? My meta-talk begins to fail me. I seem to say ‘I can say,’ but why, I can’t say.

“Do you ever think it’s curious that almost none of the people involved in diagnosis, or none of them, actually spends a significant amount of time with these demented people?” I ask, “Probably the most time they spend with anyone are the people in neuropsychology, right, and that’s a *testing* situation. Most of the people involved in diagnosing these people have never taken care of someone who’s demented. This being the case, sometimes I wonder why a closer exposure to these people is not seen as being all that important.” “Yeah, I’m not sure I agree with that actually,” says Bobby reflectively, “I know Dr. Dandas spends about an hour with each patient during the initial exam. There’s the neurological testing, and the other testing he does, sometimes he orders other tests, blood work and, uh, and then the social workers also assist in the diagnosis. If this were a smaller place, it would just be Dr. Dandas deciding what the patient has, probably not ordering Neuropsych tests, or in *very* few cases, now we do more cases with Neuropsych tests particularly due to the *research* component. It helps

with our interest in research and it's helped us get funds in the past." "Is this the reason you do such large batteries of Neuropsych tests if they're warranted, for research purposes?" I ask. "Yeah," says Bobby, "I mean if you were just trying to make money, you'd probably have a patient come here and get em in and out in one day, or two days at the most. When we do it now it takes sometimes four or five days. I'd say the Neuropsych testing would be more abbreviated at another site. There might be fewer cases and Dr. Dandas wouldn't spend as much time with the patients as he now does."

But what about the need of mysterious instruction among the Alz people; what about that very thing which they have traditionally held most dear? Has it survived, in some form or another, the Pietist assault?

"Do you think that research scientists in this area are influenced and inspired by things which they don't share with other people," I ask, "in other words, things that people say, recurrent themes? In staffing we always say that being the head of the board of a condominium association makes one more prone to Alzheimer's. Now that's only a joke, but are there recurrent themes and observations which come to influence the research or do you think they're seen as unimportant? The reason I ask is that some psychiatrists are educated to take the *content* of delusions and stuff like that more seriously, where I've found that here such things are not taken seriously at all." "Well," says Bobby, "I think there are some differences. There are some focal biases, I guess, in diagnosing, treatment and so forth. Particular delusions could have some particular relevance, I guess, particularly for the caregivers, I guess, maybe how to treat these

delusions, what importance the *caregiver* gives this delusion. I'm sure there are some focal differences but there are national groups trying to standardize diagnostic criteria."

"Do you find there's an aversion to theoretical thinking in medical research?" I ask.

"Probably not," says Bobby reflectively, "maybe, I dunno, theoretical, philosophical?"

"Sure, theoretical," I say, "you can call it 'philosophical' but I'm not talking about 'the nature of *Being*' here on this particular point, rather just wondering why it has an aversion to this kind of thinking. For example, I'm thinking of questions like: 'What is the parasympathetic nervous system?,' or 'What is the limbic system?' and if these are the *best* ways to think about this or that problem in research or diagnosis?" "Well," says Bobby, "maybe it's not an aversion but it's a *practical issue*. There's only a limited amount of time to study and there's less time than before so things which would have sparked interest years ago probably don't spark any interest anymore. I suppose a part of it is aging, your youthful enthusiasm has died, but also there's *less time* I guess to read a book and check it out. I guess you gotta try to look at *everything* to *understand* but that's a part of it, I guess, the practical issue, an issue of priorities I would say."

"Do you think you *lose* the curiosity," I ask, "or do you just learn to let it go?"

"I think you filter out things you know you're never gonna use again, probably, or are gonna be of marginal importance and you at least try, if you're successful I guess, to focus on the things that are going to be *most* important. Maybe it's like, not such a good analogy, but like a more effective thinker, or doer, or citizen, is a person who had a

photographic memory, a perfect memory. You would think a person like that would be able to accomplish a *lot* in life, right, but he couldn't, or this is the interpretation I've heard, because in everything he looked at and had an interest in he wasn't affective in filtering out what was important, making decisions. I look at it as part of the *brain*, you know, the *judgment part* of the brain was not as well developed as it should have been, although he had a photographic memory. I mean, there's some things you'd *like* to forget, right, or you know are not gonna be important, so I guess it's a hierarchical system in your *mind* somehow."

"So what *drives* the research then?" I ask, "Is it a *curiosity*? Is it a need to cure a disease? Is it professional advancement? Is it doing one's job? What *is* it?" "I'd say its probably some professional advancement," he says admittedly, "There's a lot of that. I think a lot of us have satisfaction in publishing or discovering things, or *participating*, like donating this blood info to a genetics project in Toronto which we're now doing. I guess there is some satisfaction in participating" he says, seemingly unconvinced and lacking enthusiasm.

Pietist science, as seen above, reduces the elation of breakthrough and discovery to the warm glow of a job well done or a small, charitable contribution. But it only *feigns* resignation and melancholia. Be assured that within it lies great violence, spiritual force and the release of power (upon those who dare oppose it; upon those who care for truth and disdain the lies of necessity). 'Let's talk about it and let me tell you what you're feeling.'

“Is anyone out to cure the *disease* or to find the *cause* or something like that?” I ask.

“Uh *yes*,” says Bobby, “there are people out like that.” “Do you think that’s a “*philosophical*” pursuit though?” I ask. “Umm, yeah” says Bobby, “Well it seems when I’ve talked to Robert Matthews, who’s one of the most respected researchers in the *world* I guess, and he has, I’m sure a lot of professional advancement, and *ego* even, associated with it, but with small people like *us* , I guess, there’s a certain amount of satisfaction among all the people working with something, when your participating in a very small way to help cure Alzheimer’s disease, without working to build up somebody’s portfolio, *we could* be doing some of that maybe... Actually *my* dollars could lead someone to analyze the stock market in some way, so I guess there is some of that, a *little* bit of that. Most people like that would be people who had a personal *investment*, a *personal* interest I guess. I don’t really have any such..., even though my grandfather probably had Alzheimer’s disease. I think of my mother, who’s 51, maybe she’s more at risk because her father had it...”

This science, like a great deal of terror and oppression, always comes back to the (I)nc. Who *wouldn’t* think of their mother as Bobby does; certainly not (I)nc.? So is it all shades and mirrors, this “I”?

“But you don’t think there’s a lot of fantasy out there of finding that key,” I ask, “that in just trying to think hard and relate everything that something might crystallize of

extreme value?” “Well,” says Bobby, smiling “I guess that would almost be in the category of *delusions* maybe, to believe that. But I guess it depends on what level, if you’re at the level where you could make an important contribution... My feeling is that people who understand it, understand it as pieces of the puzzle, some bigger than others. Maybe you should look at the human genome project, where sharing is most important, and has been profitable for research. Most of the researchers want to share but, at the same time, they want to take credit for any work they do.”

The world is divided into two realms say the Pious: the “I,” i.e. fantasy, and the (I)nc., i.e. necessity. But let’s not confuse necessity with fate, (I)nc. say, to do so is “illogical.”

“What is the “*practical*” knowledge derived from the foremost genetic research in this area?” I ask. “There probably *is* some practical knowledge,” says Bobby. “But,” I say, “so now we know that you have this gene and it means this statistically, then what?” “Well,” says Bobby, thinking, “I guess you discover, or better understand the biochemical pathway, or *pathways* of Alzheimer’s disease, or diseases, it may be several diseases I guess. You’re able to create drugs, for example. Like the drugs that are out now came out because the importance of Acetylcholine was understood, or it was understood a long time ago but they weren’t studying memory, I guess, and now... [he doesn’t finish the thought] The preseniline gene is a bigger piece of the puzzle I guess, because some people, if they have the gene, inevitably get Alzheimer’s in their forties or fifties, I guess. There’s something going on. Anyway it was something new and novel.”

“Praise the Lord and pass the ammunition of resistance,” says Gabriel, “the genomes have come home to roost!”

“Isn’t , in the end, genetics, since we understand *so little* about it, a *tool*, a model to make medical and social decisions and not really a *body* of scientific *knowledge* as much as it is *correlations* between things, to alter life through genetic testing and things like that *before birth*?” I ask, “I *know* there have been one or two things out there that have actually been affected by and almost cured with genetic knowledge, but for the most part it hasn’t been very *useful* in helping us with *disease*, right?” “ Well, because it’s *new*, I guess,” says Bobby, “it’s too early to judge, I guess. I think it’s gonna be *extremely* useful.” “But isn’t it true,” I say, “that to most people it’s not at all clear what genetics *is*, and what’s going on when people attribute some sort of force to genetics? Isn’t there a sort of *mythological* view in there, in that it appears to show something but, in the end, practically, it doesn’t show anything? It’s a promise in the future, as you said, but *now* it’s invested with a lot of *aura* and little else.” “I think there are a couple things,” says Bobby, “one is that, um, okay, sometimes genes, like the APOE gene, which is an *association gene*, vs the chromosome 14 preseniline gene, which says you’re absolutely gonna get Alzheimer’s and, uh, some genes are association genes, and there’s probably a very confounded way in which they figure out genetic association. The *other* thing is that, I guess is more what you’re getting at, is that we’d like to know the human genome, which we may know in its entirety, but there’s still so little understanding about how these genes do their *work* and how this gene interacts with the other and uh” “That’s

what I'm getting at," I say, interrupting, "because there's this other half of the equation which you may call the environment or, better, *life* which is as big as the universe itself."

"I think the complexity of the gene-gene interaction and the gene-environment interaction are great," says Bobby, "and I think that the gene-gene interaction, because there are so many different combinations, will be very difficult to unravel. I had the idea we should do studies in some third world countries, or *poor* countries. There's still a bit of interest in doing that kind of work. It'd be *cheaper*. I was in Bolivia a few years ago and I said 'wow, they could get more bang for their buck there.' A million dollars here might only allow you to study a hundred people while there you could study thousands." "That's being done Bobby," I say, "all over the world." Bobby tells me of his ideas about studying Alzheimer's in the Andes, something un-thought-out about altitude, oxygen and dementia.

Getting back to the daily activities of the clinic I ask about the first papers filled out by the social workers regarding every patient and caregiver who come for a diagnosis.

"What is the main purpose of the psycho-social test and forms?" I ask. "I guess the main *practical* purpose is to do the initial testing, the initial cognitive testing and to establish rapport between the caregiver or patient and the New Center, so that we can help them more and, of course, they're gonna help us by hopefully coming back and finishing the evaluation, and to insure the families are taking advantage of whatever

services may be available.” “Now these case histories, dictated onto the psycho-social” I say, “what are their function?” “Well,” says Bobby, “I guess the course of the illness is very important in diagnosing, first of all, that’s a hard part to quantify, the course of the illness, the presenting symptoms has an *extremely* valuable *role* in diagnosing.”

“The fact that they were born in Santiago de Cuba, or that they worked for Woolworth’s for twenty-seven years, what’s the purpose of *that*?” I ask. “Umm,” says Bobby, searching, “I guess it’s to establish rapport, we care about you, we want to know about you. Something like the occupation, for example, up until a few months ago I didn’t think it was at all important. It is however important to this research that we’re doing. We can write a paper about it; hopefully get it published. Maybe we can get more funds. That’s the way I think about it, I think we could streamline some of this data in the protocol, and we’ve done some streamlining. We had an idea once about a disciplinary program, going away from these protocols where we have them color-coded and the pink thing is only for social workers, neurologists shouldn’t write in that and just have one protocol, and anyone can write *anywhere*, of course some people are experts in more than one area, so that was more of a team idea, I guess. It has been streamlined though. It used to be more bulky. In cases of dementia I think it’s more important to get information that you wouldn’t get in other diseases. Also many people have psychiatric problems. We also have many depressed people who are only depressed because they have memory problems.” There is a pause.

‘Ask a strange(r) (a) question,’ they say, ‘and get a strange(r) answer.’ “But who’s the “stranger” here?” asks Gabriel repeatedly, “Is it (I)nc. perhaps?” Bobby still wants to know my game of numbers or, rather, to know what a game of numbers would look like without them. He wants me to *inform* him, which is essentially informing *on* those whom (I)nc. know in a way in which *I* know them.

“So what’s *your* impression about the protocols used in the evaluation?” Bobby asks me. “Well,” I say, “I can speak from a staffing meeting perspective because that’s my most extensive experience, in those meetings, I’ve been involved in them for over a year and a half now. Yeah, I would say the protocols are a valuable tool. I’m not sure what role it plays unconsciously, in setting you up to think of a person in one way or another. That’s a factor that’s not really clear to me, but I probably don’t think that’s *such* a major factor. It gives a human face to the people. It gives you an idea of their class and their support system, what they’ve got going for them as far as resources. So, I think its a very valuable thing. I can’t imagine staffing without it. Without it the case becomes a body on a slab. With it, it becomes a person, we can say ‘ah ha! well, if the person was a computer programmer for twenty years and he or she can’t count change, there’s a problem.’ But, I think cultural issues and things like that are extremely complex and the discipline of social work, as social workers are taught, is just not able to overcome these complexities, to test them, to reflect huge difference which may exist between, say, a small town Guatemalan and someone from Caracas whose last name is Schmidt. If sharing the same language is, as I glean, a great deal of what is meant by “cultural” in these concerns of social workers, then I suppose my grandfather would have

a great deal in common, culturally, with an elderly man in Ghana. Like I say, the psycho-social forms serve their purpose, I just don't think that well-informed social science has anything to do with them at all."

Marina's Project

For the whole 18 months I spent at the New Center, Marina, 29, the youngest social worker and amateur photographer had one big idea. Photos should be taken of each patient and attached to each case file. The idea was that it would somehow aid in remembering the details of the many people who came in and out before they could be evaluated at the staffing meeting. The face in the photo would bring back the meeting with the patient and allow one to somehow better consider his or her essence in staffing. The first time it was mentioned everyone loved the idea. Soon thereafter Dandas officially approved the idea, but it never came about, due to Marina's neglect.

Marina was never satisfied with her job. She, like many Cubans her age, born and bred in Miami, continually felt a yearning, like the Romantic poets, for "something more," but never ended up pursuing it, never getting out of Dade county for more than a few days. Somehow these photos were going to restore something that the protocol failed to capture but, along with this, was a suspicion of something dangerous. On one hand, Marina needed essence, needed a purpose beyond her powers of measurement and referral which seemed be leaving something out in their equations. On the other hand, she saw something magical, maybe a bit diabolical in possessing such likenesses; something to do with love, vanity and life which she didn't want to face, which she didn't

“like.” Marina and her Cuban-American friends had come to call themselves “Generation Ñ,” and had taken to explore and celebrate their essence as Cubans, dabbling a bit here and there with the magical and supernatural. Love and like kept them in Miami, the only place for true *Cubanidad*. It was Marina’s job to handle all the Spanish speaking patients, most of them Cuban. She grew up in the “exile” ideology, the word/community, of Hialeah where children learn the guilt of not having suffered exile and never being able to live their parents’ lives. Photos of the Anglos would have been all right, I suspect, but those of the old Cubans would have amounted to an *unwelcome* “something more.” She’d wanted to get out several times; out of her parents’ house, out of Miami and tour Europe (mostly Spain), and out of the New Center to work with teenagers in Hialeah, until Dandas offered her more money to stay. As the years drag on in exile, forever the New Year’s toast ‘next year in Habana,’ meaningless words, full of sentiment, she thinks again and again of starting to take these photos. I think again of Bataille’s “Human Face.” Just as senility in old age, a plight of the Alz people, mocks the human dignity which youth forms as the norm of being an adult, so does our present perception of ourselves stand in relation to a “younger time.” Her photographic impulse is radical, and terrifying. These death’s heads, should they be captured as such, would have the power to make absurd her own place in history and, with it, make manifest a dream to somehow live beyond it. “Enlightenment,” writes Kant, “is the emergence of one from a state of childhood, or minority, which one has brought upon oneself.” History, says Hegel, is the great spirit /the community/the word, the master and the slave in one.

New World (In Place of A Memory)

It was a Summer day at a small lake in Michigan. The lake had a small beach surrounded by woods and a path winding to a distant parking lot. I was about three. After a picnic lunch on the beach, my mom laid back and closed her eyes behind her Jackie O. sunglasses and my British Aunt Pam handed me a brown paper bag, folded over at the top and told me to go put it in the rubbish.

As I waddled off down the crowded beach I came to a big metal can. “Is this the rubbish,” I asked a man nearby? “Nope, that’s the *trash-can*,” he said wisely, so I continued on my way. I don’t know how long I wandered, off the beach and down the wooded trail looking for the rubbish, but while I wandered the whole beach was moved to state of vigilant frenzy as my mother began to have dark thoughts of her only child drowning. I remember only the beauty of the wooded scene, so peaceful in my independence and resolve to find the rubbish. Before long though I was crying and being scooped up in the arms of a woman and carried back to the beach and my young mother.

Later that Summer I remember sitting on the beautiful, blue bottom of the deep end of a pool, into which I had slipped. It was quiet and peaceful as I looked around, and then a disturbingly huge plunge as I was seized and lifted to the surface by my baby-sitter. How long had I been sitting down there, she and her friend wondered? I didn’t seem to care.

Five years later my best friend is sitting on the bank of a river where for the first time he, a group of boys from the neighborhood and I had gone swimming. He had cut his big toe on a piece of broken antique glass imbedded in the silty river bottom, and as we all watched he pinched the gash in his toe separating the flesh showing the depth of the cut before dipping it back into the cleansing flow of the river. Upon further exploration, though from that point on we all wore old tennis shoes while in the water, a whole treasure of antique medicine bottles was excavated. There must have been hundreds of small bottles, some with the corks still in them, lying there undiscovered since the 19th century when this part of the river (I came to admit much later) must have been a dump. From that day on, upon the windowsill of my room sat a whole collection of these bottles, glowing in their dark blue, brown and green luminescence as the sun shown through them, and inspiring daydreams of secret reasons for them being where we found them.

My two companions and I sat listening to every word of a water spirit healer as he sat against the light blue painted walls of his shrine, his arms folded and legs crossed, the sun setting in the dusky humidity of the Niger Delta. As he weaves curious and heart softening tales of his childhood, his illness, his abuse by other boys, his abduction and seven years living under the water, he pauses and looks at me directly. "You will see me, or someone like me in a dream," he says, alarming my friends, and then me. "But don't be scared. The water spirits are friendly, they like you."

That night, back in my room, I didn't sleep well, waiting, but no such dream came. It was a few nights later when I am standing in some dream space, a room, and across the room, at a good distance, I see someone looking at me, and as I look, in a lightning fast motion I zoom towards this image pounding to a stop right before it. It is me, staring at myself, as I wake with a start.