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An Ethnographic Case Study of *Austin Young Onset Parkinson's Group*

1. Introduction

My name is Jack David. I am a graduate student at Texas State University. I have Parkinson's Disease. I am a member of *Austin Young Onset Parkinson's Group*, which is a support group for people who have been diagnosed with Parkinson's Disease (PD) at an earlier age than average, and their family members and friends. The webpage of *The National Institute of Neurological Disorders and Stroke* states that "the average age of [PD] onset is 60 years, and the incidence rises significantly with increasing age. However, about 5 to 10 percent of people with PD have 'early-onset' disease that begins before the age of 50." For the purposes of the young onset group, the definition of "young onset" or "early onset" is subjective—anyone with PD who feels comfortable in the social context of the group is welcome.

This paper is an ethnographic case study of *Austin Young Onset Parkinson's Group*. I gathered data from personal live interviews, questionnaires, participation in group meetings, and external sources. All participants in the study have signed a consent form. All participants are anonymous. Any participant who is quoted in the paper is identified with a pseudonym.

2. Theoretical Framework

Part of the process for the development of this paper includes the identification of a *theoretical framework*—a "lens" based on a philosophy or worldview through which I examine

and analyze the data—such as feminism, Marxism, postcolonialism, or queer theory. I am a disabled individual who has Parkinson's Disease. I am also, among other things, a male, white, American, politically-conservative Christian—but all of those things are meaningless in the current research project—since PD victimizes all human beings equally, without discrimination. PD is an "equal opportunity" disease that affects men and women from all ethnic backgrounds and socioeconomic levels in every nation of the world (Christiansen 2; Sharma 4). PD does not care about my gender, race, religion, political ideology, sexual preference or social class.

Although PD afflicts people from all of the groups into which we artificially divide ourselves, this particular study is directed toward a *social* group of people who have PD—therefore a theoretical framework of the *Social Model of Disability* is applicable—a viewpoint where "disability is understood as a social and political issue rather than a medical one" (Oliver 1446). This theory identifies *impairment* as "the functional limitation within the individual caused by physical, mental or sensory impairment," and *disability* as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social barriers" (Oliver 1447).

One aspect of the *Social Model of Disability* is the unique perspective disabled individuals offer to the social understanding of disability. Michael Oliver states that "over the past twenty years, writings by disabled people have transformed our understanding of the real nature of disability" (1446). A person who is disabled has an intimate perception of the experience of being disabled, and can bring that perspective into the process of writing about or doing research on the disabled experience. Disabled people have a unique perspective of writing about the condition of being disabled—just as do women who write about feminist issues or politicians who write about political issues. Some of these disabled people who write about

disability are also medical professionals or otherwise very educated individuals, and some of them are not. Writing about disability through the lens of personal disability not only gives these writers a unique perspective, but also increased credibility regarding the subject.

For example, Jill Bolte Taylor was a neuroanatomist, a brain expert, who taught at Harvard Medical School. In 1996, Taylor suffered a stroke in the left hemisphere of her brain. She wrote a book, published in 2008, entitled *My Stroke of Insight*, in which she describes her experience from the dual perspective of a medical professional and as a stroke victim. Taylor describes her book as "a weaving of [her] academic training with personal experience and insight" (Taylor 1, 5, 6). Another book, which I cite frequently in this paper, is *Parkinson's Disease: An Essential Guide for the Newly Diagnosed*, written by Jackie Hunt Christiansen, who is not a medical professional, but was diagnosed with PD in 1998 (Christiansen xvi-xviii). Michael J. Fox, a well-known actor and musician, was diagnosed with PD in 1991 (Fox 27). Fox wrote a book entitled *Lucky Man*, a very intimate memoir of his personal odyssey with Parkinson's Disease, and the effect it had on his life and career.

This project is an *autoethnography*, a variety of ethnography where researchers "study their own backgrounds, personal histories, and present experiences as members of a particular culture as a way to make better sense of that culture" (Blakeslee and Fleischer 102). I am a *participant observer* who is "involved in the setting as an insider" (Blakeslee and Fleischer 109). I am engaging in autoethnographical research because I am a member of the group and contribute to the group dynamic. My personal experiences affect my perception of the group, and my biases will affect the way I do my research—and these biases will be reflected in this paper. I do understand, however, that I must be aware of my biases—and do my best to have an open mind.

3. Parkinson's Disease

Historical references to Parkinson's Disease date back to ancient times. In Western medical literature, it was described by the physician Galen as "shaking palsy" in 175 AD (Sharma 3). The first modern description of PD was made by James Parkinson, a London physician, in 1817 (Sharma 3-4).

Parkinson's Disease is a neurological disorder that affects the control of movement, which is caused by a deficiency of *dopamine*, a neurotransmitter or chemical messenger that is necessary for muscular control (Sharma 1-2; Christiansen 1-2). This means that your muscles do not move when you want them to—and move when you do not want them to. Dopamine is produced in the *substantia nigra*, which is part of the *basal ganglia* area of the brain. In PD, the cells of the substantia nigra die, resulting in the production of less dopamine than normal (Sharma 6). By the time PD is diagnosed, 60 to 80 percent of the dopamine-producing cells in the brain, known as *dopaminergic neurons*, are no longer functioning (Christiansen 2). No one knows what causes the death of these cells, although there are several hypotheses—which include free radicals, environmental toxins, intravenous drug use, genetic factors and aging (Sharma 6-9, 29-35).

4. The Participants of the Study

An appeal was made, in person at a group meeting, and by e-mail, to the entire membership of the group, to participate in the study. There were only thirteen individuals who agreed to participate and who signed consent forms—six (46%) males and seven (54%) females. According to Daniel, the group leader, this is about half of the active membership of the young onset group who have been diagnosed with PD. Of the thirteen participants, eleven (84.6%) were Caucasian, and two (15.4%) were Hispanic. Of the thirteen participants, twelve submitted

completed questionnaires; of these twelve, two of them also participated in a live interview. Daniel, the group leader, participated in a brief phone interview regarding the history of the young onset group. Of the twelve participants who completed a questionnaire, two had completed "some college," seven had earned a bachelor's degree, two had earned a master's degree, and one had earned a doctorate. Of these twelve, the average age was 54. A copy of the questionnaire, as it was presented to the participants, is included in Appendix A.

5. Diagnosis

The average age of PD diagnosis for the participants in the study who completed questionnaires is 48. Receiving a diagnosis of PD is a difficult process. Currently, there is no test that can be performed to confirm definitively a PD diagnosis in a living patient—the only way PD can be medically proven is through autopsy (Christiansen 9). A diagnosis of PD is a diagnosis of exclusion. Physicians order tests to eliminate other possibilities (Christiansen 7). Only after several other disorders have been eliminated, and an in-office neurological examination has been performed, can a patient who exhibits symptoms of PD be given a definitive diagnosis (Christiansen 9-10). The neurological examination includes coordination tests that are very similar to "field sobriety" tests conducted by a police officer—such as closing your eyes and touching your finger to your nose, and walking in a straight line putting the heel of one foot directly in front of the toe of the other (Christiansen 10-11).

Unfortunately, sometimes a patient receives a false diagnosis of another disorder, only to discover later that he or she actually has PD. Four of the twelve questionnaire participants initially received a false diagnosis. Luke, a 53-year-old male, states: "I was originally diagnosed as having had a brain stem stroke. I felt betrayed, and I felt insecure about putting my trust in the medical profession." Marcia, a 57-year-old female states: "[The] first diagnosis was possibly

carpel tunnel syndrome or arthritis. When the PD diagnosis was given, I was shocked." Alice, a 59-year-old female, had a similar experience:

> I saw six doctors, two of whom were neurologists. I was devastated to learn I had PD, despite the fact that in the back of my mind, I always suspected it. My father had PD and I had many of the same symptoms. I was angry that I was subjected to needless and costly back surgery prior to receiving the correct diagnosis.

Likewise, Cindy, a 54-year-old female, was initially incorrectly diagnosed with Epstein-Barr Syndrome.

Whether PD is correctly diagnosed initially, or not, when the patient discovers he or she has PD, the result is quite often devastating. Peter, a 68-year-old male, who was diagnosed at age 64, states that although his PD was

> diagnosed accurately and quickly. I felt like "oh shit". Not mad or in denial just concerned what it really meant. I had a very active, physical life, a fitness nut. Due to my occupation, I had earlier mentally resolved the fact that I could die at any time, I was just not ready however to die as an invalid (sic).

PD usually creeps up on you; symptoms appear slowly and are often not regarded seriously at first. Most people who are later diagnosed with PD knew that "something was wrong" for quite a while before their official diagnosis. Two or three years before his diagnosis, Luke first noticed trouble with his hands while playing the guitar. Greg, a 40-year-old male, noticed symptoms as much as three to five years prior to his diagnosis:

> Suspicions that something wasn't working right started when I would have terrible cramps and tremors in my right arm, but the symptoms would come and go. I became concerned (and so did my wife) when the tremor became almost

> constant at rest. I was also becoming increasingly clumsy and had a difficult time recalling certain words.

Lisa, a 40-year-old female reported that about two years before her diagnosis:

> I was sitting on the couch and noticed the middle two fingers on my left hand would close shut about a quarter of an inch every few seconds. The inside of my forearm felt like someone was plucking a guitar string—it just moved on its own. I also dropped an egg when taking it out of the refrigerator, and as I stood up on my toes to reach something in an upper cabinet, I noticed my left leg shaking.

Sometimes other people notice changes before the patients themselves do. Marcia stated that five years before she was diagnosed: "Several family and friends noticed that I was not swinging my left arm when I walked and that I held my left arm close to my body as I walked." Robert, a 59-year-old male, reported that about four years prior to his diagnosis, people at the gym commented on his stooped posture: "When I'd work out at the health club people noticed that I was bent over and very slow to turn and things like that. People were asking me what was wrong."

6. Symptoms

In my questionnaire, I asked the participants to identify and describe their PD symptoms. Any question left unanswered is assumed to be a negative response for any given symptom. In some cases, the respondent is unclear whether symptoms are caused by PD, medication, or other factors, such as aging. A complete list of the symptoms, with statistics regarding percentage of occurrence, is found in Appendix B.

There was only one symptom that was reported by all twelve respondents—stiffness or difficulty with movement. Lisa states:

> When I wake up, my left leg is stiff for [the] first minute or so. When I walk, it feels like my legs are 10 pounds heavier than they used to be. [. . .] [M]y left ankle and wrist [are] constantly turned in, and my left toes are always contracted [making it] uncomfortable [to wear] closed toe shoes.

Eleven of the twelve also experienced problems with fine motor skills using their hands. Greg states: "I make far more typos than before. My handwriting has degraded. Reassembling my electric razor after cleaning it is one of my more frustrating tasks. Mornings are usually the worst time of day [. . .] for me." Ten of the twelve respondents reported tremors, unusual gait and problems with balance—all classic symptoms of PD.

Most of the symptom percentages were about what I had expected. PD affects different people in different ways. One of them, however, surprised me. Four out of the twelve respondents—one third—reported having hallucinations. I was under the impression that this symptom manifested rarely in people with PD. While an incidence of one third may seem statistically small, I believe it to be remarkable—considering the severity of the symptom.

7. Medication

In the questionnaires, and in the live interviews, I asked the participants questions about medications they were taking for PD. They reported eighteen different medications. I found it difficult to make sense of the data I collected. Sometimes they identified medications by generic names and sometimes by brand names. I tried to find each one of them on the Internet to consolidate medications that were known by different names. Some of the medications do not appear on the Internet at all. I assume, therefore, that these medication names were misspelled by the participants. The most common medications used by the participants were Azilect (Rasagiline) (50%), and Sinemet (Carbidopa/Levodopa) (42%).

When I asked the participants if they had experienced negative side effects from PD medications, four of them reported having had negative experiences with Mirapex (Pramipexole). Cindy reported that Mirapex made her "compulsive, and sick every morning for six years." Luke stated that Mirapex caused "headaches, grogginess, anxiety, paranoia, and hallucinations." Lisa reported that Mirapex gave her "vivid daydreams and [she believes] contributed to a rash of purchases one month." Susan, a 40-year-old female, reported having experienced insomnia, sudden sleep disorder, compulsive-obsessive behavior and gambling addiction because of taking Mirapex.

8. Deep Brain Stimulation

There is a variety of treatments for PD, both real and imagined, in addition to medication—as simple and practical as exercise (Sharma 87-89), and as theoretical and controversial as embryonic stem cell research (Sharma 52-53; Christiansen 251-52). One contemporary treatment for PD, which is apparently quite effective, is *Deep Brain Stimulation* (DBS). DBS is a surgical procedure where electrodes, about the size of a piece of spaghetti, which are placed directly into the brain tissue, generate a magnetic field that regulates brain function—sort of like a brain pacemaker. Wires are implanted under the skin from the electrodes in the brain to a battery pack in the chest or abdomen. By placing a wireless control unit near the battery, the neurologist can adjust the settings (Sharma 56-57; Christiansen 232-233).

Three of the twelve respondents have had the DBS procedure. Carol, a 53-year-old female, states: "It has helped considerably. I don't have the tremors so much. The stiffness is not so bad." Cindy states: "It has given me a new lease on life. I can smell and taste again. [I can now] take low doses of meds. [It] helps with stiffness. [There is] less tremor." Robert, in a live interview, states the following about DBS:

> I can't say enough good about it. It was a miracle for me. It completely changed my life. Prior to DBS, it would take me a long, long time to turn over in bed and I would freeze. [. . .] I couldn't turn around. [After having DBS], I play basketball, lift weights, swim, and ride my bicycle. [. . .] It was a game changer for me. It made me function pretty much like normal people. You know, except for a little bit of slow speech, a little bit of a balance issue—but most people can't tell that. [. . .] I was in the doctor's office, and I looked over and it was obvious [a man in the waiting room] recently had DBS. I went over there and sat down by him and I got to talking to him and [he told me that] he had tremors so bad that he couldn't write, couldn't use his computer, couldn't drive—and he was just barely shaking after the surgery.

9. Work/Income

Five of the twelve respondents are still working, and earning income. Three of those who are not working are retired. Three of the seven who are not working are receiving Social Security Disability. Eight of the twelve respondents reported having difficulty with working because of their PD symptoms—the most common responses involved difficulty with fatigue, slowness of movement, and self-consciousness about their tremors. Lisa states:

> I have to make many presentations with the type of job I do. My entire left side shakes like crazy. I don't want people to think I'm nervous, nor to focus on "me" when I'm trying to present a new topic to them. Occasionally, I mention the tremor and that it's nothing that holds me back from doing my job, but usually I don't mention it.

10. Personal Interactions

I asked the participants a few questions about their daily interactions with others. Six of the twelve have noticed strangers staring at them in public. Marcia states: "If I am having PD symptoms at home, I postpone going out in public. If symptoms begin in public and medication does not eliminate symptoms, then I try to get home as quickly as possible." Luke states: "Many people lack the social skills required of polite society. I surmise that people notice that there's something 'wrong with me.'" Cindy responds positively: "I will address my PD with people. I made a decision a long time ago to live my life passionately—with grace, beauty, and laughter. If someone stares—it's their problem, not mine—so I smile at them and let it go."

Four of the twelve have found most strangers they encounter to be helpful, such as opening doors for them, or offering to help them carry something. Lisa states: "I've been amazed at how kind [. . .] my friends have been—and also at the kindness of strangers." Luke, on the other hand, has a different perspective: "I find that people who are about 30 years old or older are very courteous and offer to help; however, younger people tend to be more likely not to care if they knock me down if I get in their way."

11. Capital Area Parkinson's Society

According to their website:

> Capital Area Parkinson's Society (CAPS) was founded in 1984 to address the needs of people with Parkinson's Disease, their families, friends and care partners. CAPS is a non-profit organization, serving the Central Texas community. Membership in CAPS is open to anyone with an interest in Parkinson's Disease. CAPS provides those impacted by Parkinson's Disease, many of whom may know very little about their disease, a forum in which to discuss their situation with

> others similarly afflicted. CAPS offers care partners a support group in which information on the care of Parkinsonians can be received and exchanged, and through which the needs of the care partner can be addressed. In addition, CAPS provides a forum for the discussion and dissemination of new information on Parkinson's Disease and related areas.

CAPS is the parent organization of *Austin Young Onset Parkinson's Group*. However, only five of the twelve respondents are also members of CAPS. As I stated in the introduction, "the average age of onset is 60 years; however, about 5 to 10 percent of people with PD have 'early-onset' disease that begins before the age of 50" (*National Institute*). Since most people with PD are 60 and older, PD patients who are in their 40s and 50s frequently feel "out of place" in a social setting consisting of the geriatric majority. Quite often, they are still working for a living, and are more physically, mentally, and socially active. Unfortunately, CAPS tends to focus more on the needs of the older patients. Cindy states: "[CAPS] doesn't reflect my life. [It has a] different focus [for an] older group. [We have] nothing in common. [We are] not even [in] the same kind of stages of PD." Robert spoke of his experience with CAPS in a live interview:

> Everybody was nice there, but everybody was old and decrepit, and they were doing this little therapy thing that wasn't for me. My therapy's playing basketball, lifting weights, swimming, and riding my bicycle. I didn't want somebody up there singing, and me having to do this kind of stuff [pantomimes arm movements]. I'm sure it's valuable for those people, but, I've gotta fight this in my own way. When I get to the point where I'm slumped over and drooling,

> I'll do their little things and that'll be a victory, I guess, if I can just move my arms a little bit—but right now that's not where I am.

12. Austin Young Onset Parkinson's Group

Austin Young Onset Parkinson's Group, the subject group of this study, is an auxiliary organization of Capital Area Parkinson's Society, which addresses the needs of people who have been diagnosed with Parkinson's Disease at an earlier age than average, and their family members and friends. In 2007, the leadership of CAPS recognized the need for a young onset group, and asked Daniel to organize and lead such a group. The young onset group was organized in February 2008. Daniel, an active member of CAPS, looks for new faces at the CAPS meetings, who appear to be younger than average, and tells them about the young onset group. Four of the twelve participants in this study learned about the young onset group through Daniel's efforts at CAPS meetings, three of them learned of the group from their doctors, three from the Internet, and two from other sources.

In my questionnaire, I asked for their impressions about the young onset group. Robert describes them as "good people, banding together for a common cause." Peter describes them as "real people with real problems." Cindy describes them as "a great group, not a group that has a pity party. They are people [who are] positively, bravely living life with PD." Greg was initially apprehensive about attending a meeting of the group stating that he was "a bit afraid to look the future in the eyes." Luke states:

> I was initially intimidated by the group, because I am very shy in new social situations with groups of strangers. This was compounded by the fact that the [first] meeting [that I attended] was held in a very small room—and I am claustrophobic. The only thing that I really have in common with these people is

> that we have the same disease. However, I have learned a lot about PD and been exposed to sources of information that I would not have otherwise known about.

Lisa states:

> I felt very welcome and it was terrific to hear people discuss symptoms similar to mine. But we spent little time on our problems, and it was uplifting that our leader, [Daniel], brought optimistic news reports of all the clinical trials, and advances in treatments. I could tell that [Daniel] was an engaging, caring and optimistic individual; he really set the tone for the group. [. . .] Sometimes it's a bit of a downer—seeing people with symptoms that are debilitating.

13. Team Dopamine

Before he was diagnosed with PD, Daniel was an avid bowler. I remember him telling me, in a casual conversation, that he first knew that "something was wrong" when he started having difficulty bowling. Physicians and rehabilitation experts continually stress the importance of exercise for PD patients. With this in mind, Daniel founded *Team Dopamine*, a bowling team consisting entirely of people with PD, who meet every Tuesday to socialize and get some much-needed exercise in a safe environment. There are currently about 14 people with PD, from the young onset group, who participate in two teams. Team members wear uniform shirts with the slogan "Parkinson's Sucks" boldly imprinted on the back. Daniel states that the goal of Team Dopamine is "to get out, as a group, and interact with 'normal' people, and have a good time, and maybe show them something about people with Parkinson's too—that we can get out there and kick some butt just like anyone else. We just look funnier and we do it slower." Daniel hopes to expand the Team Dopamine franchise beyond Austin, and establish bowling

teams in other cities. Team Dopamine was featured on KXAN Austin News at 10 on January 31, 2010.

Peter, who bowls on Team Dopamine, states: "[I have] never bowled in league play, but I look forward to bowling each week with the team. We don't have to apologize for having PD. We are just like the rest—some days are better than others." Lisa, another team member, states:

> What a great outlet our bowling team has been. The camaraderie and laughter is very welcoming. We may talk a bit about what we're going through regarding PD, but primarily it's just fun. And the other teams we play against seem to really enjoy us and not mind when we trip, or simply bowl poorly. Also it's been inspiring to see some of us with more serious symptoms still be good bowlers. It's great for our morale and attitude.

14. Communication and Literacy Issues

While engaging in casual conversation at group meetings, and elsewhere, about this ethnographic case study, several people asked me what my study had to do with English—since I am, after all, pursuing a master's degree in English. An ethnography is a multi-discipline endeavor—with elements of such fields of study as anthropology, sociology, psychology, and others. The consent form that all of my participants signed states the following:

> This study explores the group's contribution to the social needs of individuals with Parkinson's Disease and the literacy practices within the group. For the purposes of this study, "literacy practices" is defined as "any communication of thoughts, feelings, or emotions by verbal or non-verbal means."

This supports a theoretical framework of the *Social Model of Disability*—where "disability is understood as a social and political issue rather than a medical one" (Oliver 1446). My goal,

then, was to examine the discourse of the group, and individual members of the group—to discover what they talk about, and what impact it has. The reason that I expended so much effort on subjects such as diagnosis, symptoms, and treatment—is because those subjects are the ones about which members of the group are concerned, and which dominate their discourse.

As I stated earlier, my personal experience with PD made it impossible for me to be totally objective while doing this research project. My biases affected every stage of the process—starting with the questions that I asked in the questionnaire, and in the interviews. I devised these questions based on my experience with PD, but I was also influenced by things I have read about PD, things that doctors have told me, and what I knew to be the concerns of people in the group—from group meetings and from personal conversations with group members.

In an attempt to accommodate the special needs of my participants, I distributed the questionnaires electronically. I created a Microsoft Word document, emailed it to the group and asked the participants to "respond to each question by editing [the] Word document" and emailing it back to me. Because of PD, I have extreme difficulty with handwriting—I can barely sign my own name, or jot down a few words. I assumed that my participants, to varying degrees, experienced similar difficulty. I thought it would be much easier for them to use a computer to complete the questionnaires than it would be to write them by hand. In addition, the majority of the participants live in Austin, and I live in San Marcos, 35 miles away—and driving is an issue for me. I tried, to the best of my ability, to make the process of exchanging information as easy as possible for my participants.

Despite my best efforts, the process of communication was, at times, quite challenging. Early in the semester, January 24, 2010, at a group meeting, I announced my intention to feature

the young onset group in my ethnography. I received very positive feedback from them, and they were apparently quite flattered that I wished to write about them in a graduate-level paper. I devised a rough draft of the questionnaire and emailed it to the entire group, asking for feedback—including questions that I should have asked on the questionaire, but did not. I only received a few responses to this request, but some of these responses were very helpful. On February 26, I emailed the revised questionnaire to the entire group with a request to complete and return them. On March 5, I had received only three responses, so I sent another email to the group to remind them. On March 9, I received an email from a group member stating that my questionnaire was "too time consuming," and that I should rewrite it, and make it shorter. I responded to this email by explaining that I had finished my revisions of the questionnaire several weeks prior, and had already received five completed responses. On March 23, I had only received a total of seven responses, and I was beginning to panic—so I sent yet another email to the group, explaining that I was facing a deadline for data collection and all the group members who wished to participate had to return their questionnaires by April 1. On April 1, I had received twelve questionnaires, and I sent an email to the group informing them that I could not accept any more responses, because my final paper was due on April 29. I had hoped to have more than twelve completed questionnaires, but I did the best that I could with what I had.

Another breakdown in communication involved the failure, by many of the participants, to follow simple instructions. My instructions included this statement: "Please be as detailed as possible with your answers. Even if a question appears to require a one-word answer, or to be a yes/no question—please respond with at least a few sentences if possible." Most of the participants ignored this request, and responded with one-word answers. One participant, when I asked the question: "What do you know about DBS?" responded with this comment: "Enough to

make this answer too long for me to type." I consider this response to be insulting and sarcastic. This person could have just as easily responded with a short answer using the same number of characters. Thankfully, there were several participants who appreciated the opportunity to have their voice heard, and submitted well-thought-out responses.

15. Conclusions

My primary purpose for this study is to give a voice to ordinary people who have Parkinson's Disease. If I have succeeded in that quest, then all the frustration I encountered was worth it. In evaluating the questionnaires and the live interview transcripts, I get the impression that most of the people in the group are more concerned with their personal experience with PD than they are with their experience with the group. I conclude that the only thing that I have in common with most of the individuals who make up the young onset group is that we have the same disease. Other than that, it is just a random group of people that is thrown together—with the same proportion of "nice" people and "not so nice" people as are found in the general population. I freely admit that I feel awkward in most social environments, and that my perceptions affect my evaluation of this group. I believe the members of the bowling team share the strongest friendship bond because they are taking a proactive stance in overcoming the ravages of this terrible disease, both physical and emotional. At the end of the day, the mantra which is proudly displayed on the Team Dopamine uniform shirts is the ultimate truth—"Parkinson's Sucks."

Appendix A

Parkinson's Disease Study – Questionnaire

Instructions: Please read through the entire questionnaire carefully, then respond to *each question* by editing this word document. Move the cursor below the question and enter text. Don't worry about formatting, or how it looks. Save the document with your changes and email the edited document to me at jackhdavid@thehouseofdavid.com.

These questions are directed to people who actually have Parkinson's Disease, but input from family and friends is also appreciated in the sections on "The Group" and "Anything Else". Please be as detailed as possible with your answers. Even if a question appears to require a one-word answer, or to be a yes/no question—please respond with at least a few sentences if possible. Feel free to express any personal reflections or feelings regarding any question. Please be honest, even with questions that may seem very personal or embarrassing. Be assured that your identity will remain confidential. Any reference to individuals in the final report will use pseudonyms. If there is something that I neglected to ask that you consider important, or something that you just want to express, please write it at the end of this document.

Demographics

What is your gender?

What is your race/ethnicity?

What is your highest level of education? (high school, vocational school, college, etc.)

What is your current age?

Diagnosis

Do you have a diagnosis of Parkinson's Disease? If yes, please continue the questionnaire; if no, go directly to the section on "The Group."

What was your age when you were officially diagnosed with PD?

Did you receive a false diagnosis prior to being correctly diagnosed with PD? If so, what was the false diagnosis? How did you feel when you discovered you had been incorrectly diagnosed?

How long before your official diagnosis did you experience PD symptoms?

Describe the first time you suspected that "something was wrong."

Has a neurologist or other physician confirmed a definitive reason that you have PD? (brain trauma, exposure to environmental toxins/chemicals, genetics, etc.)

What is your personal belief about why you have PD?

Do you have a family history of PD? If yes, describe.

Do you have any other diagnosed illnesses? (hypertension, diabetes, etc.) If yes, how do these illnesses interact with PD?

Symptoms

Please indicate if you believe that these symptoms are unrelated to PD or are caused by medication. If the answer is "yes" to *any* of these questions—*please describe your experience*.

Do you experience tremors?

Do you experience muscle stiffness or difficulty with movement?

Do you experience problems with fine motor skills using your hands?

Do you experience difficulty with handwriting?

Do you experience difficulty with typing?

Do you experience difficulty with cooking?

Do you experience difficulty with eating?

Do you experience difficulty with swallowing pills?

Do you experience difficulty with dressing?

Do you experience difficulty with bathing/showering?

Do you experience difficulty with personal grooming? (shaving, etc.)

Does someone who lives with you help you with these or other daily activities?

Do you experience difficulty with balance?

Have you ever fallen because of PD?

Do you experience difficulty with walking?

Do you use a cane, walker or similar device when walking?

Do you experience unusual gait? (shuffling, freezing, lack of arm swinging, etc.)

Do you experience restless leg syndrome?

Do you drive a motor vehicle?

Has anyone told you that you don't smile, make eye contact, or otherwise commented on your facial expression?

Do you experience difficulty with speech? (stuttering, lip/tongue paralysis, voice projection, etc.)

Do you experience difficulty with your eyes/vision?

Do you experience difficulty with hearing?

Do you experience problems with choking? (food, water or other liquids, your own saliva, etc.)

Do you experience problems with control of your saliva? (drooling)

Do you experience pain that you associate with PD?

Do you experience problems with your digestive system such as diarrhea or constipation?

Do you experience problems with urinary incontinence? (control of urine)

Have you ever experienced problems with sexual functioning?

Have you ever experienced problems with mood disorders such as depression or anxiety?

Have you ever experienced delusional thinking such as paranoia?

Have you ever experienced cognitive difficulties such as memory loss or difficulty with concentration?

Do you experience problems with sleeping?

How many hours do you usually sleep in a 24 hour period?

Have you ever experienced vivid or disturbing dreams?

Have you ever experienced hallucinations? (visual, auditory, tactile, etc.)

Describe any other PD symptoms that you have experienced that have not been addressed in this questionnaire.

Medication/Treatment

If the answer is "yes" to *any* of these questions—*please describe your experience*.

What medications are you taking for PD?

Do you believe that the medications help? How so?

Do you experience adverse side effects from the PD medications?

Are there any PD medications that you *were* taking, but had to discontinue because of the side effects?

Do you exercise regularly to improve your PD symptoms?

What other treatment do you receive for PD?

Deep Brain Stimulation

What do you know about DBS?

Have you had the procedure? If so, tell us about your experience; if not, would you consider it? Why or why not?

Work/Income

If the answer is "yes" to *any* of these questions—*please describe your experience*.

Are you able to work for a living?

How does PD affect your ability to work?

Does your employer provide special accommodations for you?

Did you find it necessary to change your job because of PD?

Are you on Social Security Disability?

Personal Interactions

If the answer is "yes" to *any* of these questions—*please describe your experience*.

Do you feel as if people are staring at you when you are out in public?

Have you ever noticed children seeming to be intimidated or even frightened by you?

Do you find most strangers you encounter to be helpful, such as opening doors for you, or offering to help you carry something?

Do you ever ask strangers for help?

Has a stranger ever assumed that you are mentally disabled, and reacted to you in a condescending manner, such as speaking very slowly?

Do you feel as if your peers at work or school think of you as creepy or weird?

Do you feel as if your peers at work or school resent any special accommodations that are made in your behalf because of your disability?

Communication

If the answer is "yes" to *any* of these questions—*please describe your experience*.

Does your neurologist and your other physicians communicate with you in a manner that you can easily understand without seeming condescending—or do they "talk over your head"?

Does your knowledge regarding PD come primarily from your neurologist, or from books, the internet, and other sources?

Do your family and friends, who don't have PD, seem genuinely interested in PD—or do they seem to be uncomfortable with the subject?

Do you feel that the only people that you can really talk to about PD are other people who have the disease?

The Group

How did you first hear about the *Austin Young Onset Parkinson's Group*?

What was your first impression of the group?

Has your opinion of the group changed?

How has the group contributed positively to your life?

Do you participate in *Team Dopamine*? (bowling team) If yes, describe your experience.

In your opinion, what changes could be made that would improve the group experience?

Do you also belong to Capital Area Parkinson's Society?

Anything Else

Please feel free to express anything else you want to say. Be as detailed as you wish.

Appendix B

Symptom Occurrence Percentage from Questionnaire

Tremors	10/12 (83%)
Stiffness or difficulty with movement	12/12(100%)
Difficulty with fine motor skills using hands	11/12 (92%)
Difficulty with handwriting	11/12 (92%)
Difficulty with typing	10/12 (83%)
Difficulty with cooking	07/12 (58%)
Difficulty with eating	04/12 (33%)
Difficulty with swallowing pills	06/06 (50%)
Difficulty with dressing	06/06 (50%)
Difficulty with bathing/showering	04/12 (33%)
Difficulty with personal grooming (shaving, etc.)	07/12 (58%)
Difficulty with balance	10/12 (83%)
Fallen because of PD	03/12 (25%)
Difficulty with walking	07/12 (58%)
Unusual gait (shuffling, freezing, lack of arm swinging)	10/12 (83%)
Restless leg syndrome	07/12 (58%)
Don’t smile, eye contact, facial expression	05/12 (42%)
Difficulty with speech (stuttering, lip/tongue paralysis, voice projection)	08/12 (67%)
Difficulty with your eyes/vision	07/12 (58%)
Difficulty with hearing	03/12 (25%)
Problems with choking	09/12 (75%)
Problems with control of saliva (drooling)	09/12 (75%)
Pain from PD	09/12 (75%)

Problems with digestive system such as diarrhea or constipation	08/12 (67%)
Problems with urinary incontinence	07/12 (58%)
Problems with sexual functioning	04/12 (33%)
Mood disorders such as depression or anxiety	09/12 (75%)
Delusional thinking such as paranoia	03/12 (25%)
Cognitive difficulties (memory loss, difficulty with concentration)	08/12 (67%)
Problems with sleeping	09/12 (75%)
Vivid or disturbing dreams	07/12 (58%)
Hallucinations (visual, auditory, tactile, etc.)	04/12 (33%)

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