

CO-CONSTRUCTING MEANING: AN ANALYSIS OF FAMILY CONVERSATIONS WITH
A MAN IN THE LATE STAGES OF PARKINSON'S DISEASE

by

AMY ALEXANDRA HELEN HEATON

(Under the Direction of Mariana Souto-Manning)

ABSTRACT

Approximately 80-90% of people with Parkinson's Disease (PD) suffer from speech impairments that result from the general loss of motor control associated with the disease (Letter, Santens, & Van Borsel, 2005). While researchers in the biomedical tradition have studied speech in people with PD in order to characterize the speech deficits and to assess the overall progression of the disease, there is sparse research that examines the social-interactional aspects of how PD affects the communication of individuals with PD and their families (Robertson, 2006). This dissertation examines how one man who has had PD for over 20 years co-constructs meaning in conversations with his family. Using a hybrid of Discourse Analytic and Conversation Analytic methods, this study identifies and describes in detail the strategies that family members use to understand a member who has almost completely lost his ability to make distinct speech sounds. The conclusions of this study have a wide range of implications both for the field of Linguistics and for application in speech therapy. Specifically, this research demonstrates that linguistic competence does not reside within the head of an individual (Goodwin, 2004), but rather within the community of speakers who have a shared history of speaking with one another. Additionally, this study suggests that instead of focusing speech

therapy on exercises that attempt to train a degenerating vocal apparatus in a clinical setting, the provision of therapeutic services should focus on training the community of speakers along with the individual with PD as they are embedded within their ordinary social and functional activities.

INDEX WORDS: Co-construction, Parkinson's disease, Conversation Analysis, Discourse Analysis

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AMY ALEXANDRA HELEN HEATON

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AMY ALEXANDRA HELEN HEATON

Major Professor: Mariana Souto-Manning

Committee: Kathryn Roulston
Douglas Kleiber
Betsy Rymes

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
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DEDICATION

I dedicate this dissertation to the Uebelhacks, The Heatons, The Klausses, The Nolans, and all other families who care for family members in their own homes. Your extraordinary compassion and efforts to care for your loved ones despite unfathomable hardships are the true face of humanity. Thank you for providing the inspiration and background for this work.

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CHAPTER 1: INTRODUCTION

Prologue

As his body slumps down and to the right against his will, he attempts to dig his heels into the floor and push his body upright in his wheelchair. The overused brakes slip, allowing the wheels to roll him away from the kitchen table. Somebody gets up to push him back under. And so begins his Sisyphean struggle to remain close enough to reach his food for the duration of the meal.

His food has been cut up for him into manageable bites and he either feeds himself with a spoon or has his dinner fed to him, depending on how his cocktail of medicines is affecting him at the time. If he does have the muscle dexterity and strength to feed himself, he will also have dyskinesias: over-exaggerated, jerky, involuntary, and uncontrollable movements that are caused by the medicines given to counteract the utterly catatonic state that eventually results from Parkinson's Disease. Choosing to avoid the horrifying feeling of being stuck in a "black hole," incapable of any movement whatsoever and barely able to even call for help, he has been taking these medications for about twenty years. The dyskinesias are said to be a sign that the medicines are "working". Unfortunately, this "work" they do to incite some movement results in an unruly circus of too much movement.

Once he finally manages to get food on his spoon, the route from his plate to his mouth is anything but a straight line. The dyskinesias derail all his intended paths of movement and take his arm on an unplanned journey before he can take a bite. He starts with ambitious amounts piled on his spoon to compensate for the food he will lose to the table, his lap, or his chest.

Annoyed by his failure and self-conscious of the mess he is making, he seems incapable of gathering his next bite until he has cleaned up all the lost bits and pieces. This process generally takes several minutes each time. Although a family member has had to push his chair back up to the table once already, the action required for his clean-up mission and the involuntary leg movements caused by the dyskenesias necessitate yet another re-situating of his wheelchair.

Still determined to do everything himself, he makes a motion toward his glass, an action that is truncated by his wife. Her quick reflexes are trained by years of pre-empting disasters. He almost never gets away with reaching for his drink without a family member predicting his intention and stepping in. As he has virtually no feeling left in his fingers, he cannot be trusted to grasp anything as volatile as a glass of liquid. Instead, his wife instinctively reaches over to pick up the glass and holds it for him while he takes his drink through a straw.

On certain nights, he drops his spoon onto the plate out of disgust with his failing body and pure, honest exhaustion. Someone then steps in to feed him. But this is not the case tonight. Tonight, he is in good spirits because his children are home for the weekend. His good mood translates into unflinching determination and he continues to eat on his own. While he is dedicating all his energy to the challenge of getting food and drink into his body, the rest of his family members have almost finished their meals despite carrying on a lively conversation without him. His wife has been talking about the day's events at the senior day care center. She gathers information about her husband's day from the nursing staff at the center when she picks him up in the evening. She knows he will be too tired to make the effort to tell her anything himself. Tonight, she recounts the story she collected about a wheelchair sales representative who came to the senior center to see which of the clients were in need of new equipment. She

explains how the salesperson strongly recommends brand new equipment for clients even when they are not yet in need.

While his wife finishes telling the story, he concentrates on his food. Generally, his tremendous appetite keeps his speech articulators occupied, rendering him unable to participate in most discussions. But tonight, he finds a break in the conversation and chimes in with a commentary that sounds something like,

“Zherfersumpeplsumsepistinpaincotinafinabildin....an....an...zeyaltidegetout.... an zhersonlyanlan l....ele-¹”

“Woh, woh, woh – what are you saying?” his daughter interrupts.

As he repeats his thought, his neck and head muscles have now gone dyskinetic. Even the muscles that control his eyelids are in such spasm that they remain mostly clenched shut despite his best efforts to make eye contact with his family. With his head bobbing rhythmically from side to side and in a raised voice he says, “sumpeplpeplinpain....cotinafi...inabildin -”

Again, his daughter interrupts and, trying to ferret words out of his stream of sounds, she asks, “Wait – what? You’re in pain?”. He has abandoned his spoon now and seems to be fiddling with the wheel or brake lever on his wheelchair, so she assumes he is trying to comment on a physical problem he is having at the moment. “What’s caught? Is your finger caught on something? Your pants – on your wheelchair?”

“**NO!!** Sumpepl in pain -”

“Wait. *Some people* are in pain? You mean the people at the center?” she asks. “I bet they *are* in pain from sitting in those same wheelchairs all day,” she offers sarcastically, hoping she’s made the appropriate connection between his contribution and their ongoing conversation topic.

¹ I ask readers to allow creative license in this prologue, as it is a narrative, written in the style of a novel. I am therefore not adhering to APA guidelines here.

“No, no, no.” And then, shaking his head he sighs, “Oh God.” After a brief but painful silence, he focuses his energy and shouts, “In Sspain! In Sspain! In **Ssspain!!**”

“**Ok**, ok, ok you don’t have to yell,” retorts the daughter, knowing full well that in fact, he does have to yell. As people with Parkinson’s gradually lose control over all their muscles, they not only have difficulty getting their teeth, lips, and tongue to move appropriately to form distinct speech sounds, but they also lose the ability to phonate, or “put air behind” their words. Her father has lost the ability to control his volume, so he either speaks so low it is almost inaudible, or he yells.

“So, some people in Spain? Is that what you’ve been talking about?” she asks. This is the first time she realizes that he’s not actually talking about something directly implicated in the room with them or something related to their conversation. *Maybe he’s re-telling a story he heard on the news*, she thinks.

“Some people in Spain r.r..cotinafi...inabilding....,” he continues.

“Some people in Spain were caught in a fire in a building? When? Did this just happen today? You saw it on the news?”

“No, no....fogetit,” he says dejectedly and then he picks up his spoon to start eating again.

During the next few moments of silence, his wife, daughter, and son-in-law continue thinking about what he might have been trying to say. In their heads, they re-play his comments and try to make some sense out of the words they think they have understood so far. Suddenly, there is a break in the case:

“Peter, are you trying to tell your joke?” asks his wife. She has finally realized that this is one of the dozen jokes she has heard her husband repeat many times during their 35 years of marriage.

“Yes, yes, that’s right,” he says rather intelligibly now, though his face is completely deadpan. This is partly due to his dry British sense of humor and partly a result of the “frozen mask” of Parkinson’s disease. As people with Parkinson’s lose the ability to control their facial muscles, their faces freeze into a blank expression. His face betrays none of his emotions and gives his family no clue that he might be telling a joke.

“Ok. So, there are people who are caught in a fire in a building in Spain, right?” asks his wife.

“Yes, thassit”, he says, approving her summary with a quick nod.

“And then what happens – something about an elevator or stairs or something, right? They’re trying to get out, right?”

Taking the bait and re-energized after receiving help, he continues telling his joke, “yes, thersumpepl an.... Some...r sepatists...an..sum aren’t an...zher cotinafi n...
.an...sumffzpepltake....stairs... an...an... some...some...take an...uh.... levator wz zuh
sepatists took...uh...levator...an...uhzerstukzuh stairs....and.....ones who
tukzuhstairsrsafe.....and....ones who tukuh...uh...levatoraldide....and-”

“Ok, hold on. So, there’s some people who are in a building that’s on fire and some of the people take the elevator and some take the stairs and the ones who take the elevator all died?” asks his daughter, trying to verify that she’d understood and perhaps helping her husband catch up as well, as he still finds his father-in-law’s speech difficult to interpret at times.

“Yes, thasright.” He has forced his eyes open widely now, which is usually a sign that his interlocutors are on the right track and that he is fiercely committed to finishing what he has started. “...but...uh.....uh....but, ones in levator r...r..septist..in...Spain sepatist.”

“What? The ones in the elevator are what?” his daughter asks, trying to display that she has gotten most of what he’s saying but just lacks a few words here and there. She knows there are only so many times she can ask him to repeat himself before he gives up and ends the conversation permanently, leaving his family members to contemplate their own failure and general inadequacy.

“zher sepatists in Spain....nvermin...anyway, Moral of zhetory is.....is...donput all your baskwuneggzit,” he finally finishes.

“Did you say ‘don’t put all your *Basques* in one *exit*?!’ Oh – now I get it!! You were saying the people in the elevator were Spanish SEPARATISTS! That’s hilarious, Dad!” she says, laughing. “Where did you hear that?”

“Don’t know,” he says, with a subtle smirk just barely creeping across the corners of his mouth. As he re-focuses his energy on eating his food that has gone cold, his daughter, wife, and son-in-law all look at each other, shake their heads in disbelief and smile. It doesn’t matter now that it took nearly ten minutes for this man - this father and husband - to tell a joke. Despite severe physical limitations, he has orchestrated this complex conversational exchange and obliged those around him to work with him in co-constructing meaning.

Interpreting the Prologue

This scenario is representative of a typical dinner conversation in my family. Readers may have deduced that I am the daughter in the scenario, working through meanings with my own father, mother, and husband. The data for this dissertation come from approximately 23

hours of videotaped conversations such as these recorded from April, 2005 to June, 2007. The transcripts I include in the analysis section will provide a means to view the external details of conversational action, but they cannot adequately illustrate the severe physical and emotional stressors with which a man who has had Parkinson's Disease for 23 years must contend while attempting to make substantial contributions to family conversations.

This prologue is also designed to initiate readers into what it feels like to be a family member continually collaborating with this man and earnestly trying to relate his sounds to meaningful ideas. As a daughter who has intimately followed the progression of his disease, I have become aware of my own reasoning patterns that help me to infer meaning during discussions with my father. It is my hope that the above narrative has revealed these reasoning strategies in a way that is more accessible and profound than a face-value interpretation of a transcript. In addition, the narrative is designed to put a human face on my introduction to Parkinson's disease so that readers may better understand the urgency of the research project that follows and imagine more clearly the tremendous possibilities of improvements to quality of life for families coping with this disease.

In the passage, we see that although my father's physical limitations prevent him from making distinct and readily intelligible sounds, his underlying cognitive abilities and desire to make creative contributions to family interactions remain intact. Despite his disability, he is still able to deliver complicated jokes. Yet, how is it that he is able to do this? How is it that we come to converge upon any common understanding of what my father intends to communicate? As I begin to answer these questions that are the broad focus of this dissertation, allow me to revisit the narrative.

Returning to our story, we see that there are several times when my father's relationship to the physical environment is instrumental in the interpretation of his meaning. As he moves his arm across his plate in the direction of his glass, my mother predicts that he wants to have a drink. When he is fidgeting with his wheels or brake lever, I try to associate the words he is trying to express with the objects he is giving his attention to. We rely on his head nods and his raised eyebrows to tell us that the candidate meanings we supplied for him are accurate. Although we sometimes misinterpret the focus of his interactions by orienting to material items in the immediate environment, the particular ways in which he co-deploys body movements in physical space along with his speech are often significant clues in the process of negotiating his meaning. In this dissertation, I will call semiotic interactions that rely on the material and physical context the process of Environmental Indexing (EI). A detailed look at the mechanics of the EI will come in Chapter 5.

Readers may have noticed another strategy we rely on to co-create meaning. In the narrative, once I realize that Dad is not trying to comment on any object or state of affairs in the room with us, I begin helping him build toward his meaning. In several cases, my efforts take the form of demonstrating what I have understood from his utterances and then allowing him to either approve or dismiss my candidate understandings. As we work together to narrow down his meaning, I offer, "You're in pain?" then, "*Some people* are in pain?" and getting closer to his meaning, I eventually ask, "So, some people in Spain?" These displays of where I am in my understanding allow Dad to fill in the blanks.

When I offer, "Some people in Spain were caught in a fire in a building? When? Did this just happen today? You saw it on the news?" Dad's response is to abandon the topic. It seems my understanding is too estranged from his intended meaning for him to want to continue the

extraordinary efforts it will take to orient me to the context of his joke. Interestingly, I am quite close to uncovering Dad's words, but as I still have not realized his utterances are embedded in the context of a joke, the meaning of these words is uninterpretable.

During the rest of the interaction, My Mom and I continue to offer what we have understood, providing increasingly more of the joke as we move on. Throughout this conversational exchange, Mom and I use scaffolding to progressively build an understanding of what Dad is saying. This technique serves to demonstrate our current understanding so that Dad can concentrate on filling in only the parts of his utterance that remain misunderstood. Scaffolding will be the focus of Chapter 6 .

Readers may also have been intrigued by my mother's ability to index Dad's utterances with the familiar family jokes. In general, when any person outside of our family is patient enough to attempt conversation with my father, they naturally tend to use environmental indexing and scaffolding strategies. They attempt to situate his speech in the immediate physical or conversational context. When this process fails them, they generally appeal to my father's accompanying family members for translation help. There are very few occasions when my family cannot eventually figure out what my father is saying. Referring again to the narrative, we can see that there is a lull in the conversation while the three of us try to match up the parts of my father's utterance that we have understood up to that point with our stores of past experiences in conversations with him. Combined, we all have over fifty years of training for moments such as these. We know him well enough to be familiar with the types of things he is likely to say. My mother finally is able to recognize the elements of a joke she has likely heard him tell dozens of times in their personal history together. It is only by virtue of this family history that she is able

to find an index for his utterance. This ability to find meaning based on a lifetime of experiences will be called the Life Narrative, and will be addressed fully in Chapter 7.

While my family's conversations may seem anomalous due to my father's disease, I argue that our dialogues actually serve as a laboratory for investigating the processes through which all human beings interact conversationally and co-create meaning. As my family works collaboratively over multiple turns to decipher meaning from his strings of indistinguishable sounds, we provide a slow-motion window through which to view the social creation of meaning as an ordered process. The lengths my family goes to in order to communicate with my father also underscores how fundamental the desire to understand one another is to human nature.

Delivering a Joke Without the Hindrances of Parkinson's disease

If we imagine a scenario that is different from that described in the prologue, where the joke-teller would be a man unaffected by Parkinson's disease, his delivery might go something like the following:

So there were some people – some separatists – who were caught in a fire in a building and to get out, some of the people took the stairs, but all the separatists took the elevator. The ones who took the stairs all got out safely, but the ones who took the elevator all died. And you know what the moral of the story is? Don't put all your Basques in one Exit (delivered with the British Received Pronunciation "g" and "z" to indicate "eggzit").

This man might carry a smirk on his face or use different tones of voice to indicate that he is telling a joke. His intonation, pauses, and timing would likely also help his interlocutors to understand his joke. The joke would probably only take about 20 seconds to deliver and it would

be unlikely that his audience would become as involved in the meaning negotiation process as the family of a man with Parkinson's disease.

Cases where my father's interlocutors are able to correctly interpret my father's meaning on the first try are increasingly infrequent. Indeed, in my father's first attempt at an utterance, there may be no sounds that we can pin to meaningful words. As his disease progresses, we find ourselves needing more conversational turns to negotiate a common understanding. In a first cursory layer of analysis where I simply watched the video footage, I noticed that the interactions where we had the most difficulty arriving at an understanding tend to reveal the processes of meaning making the most clearly. The audience of our theoretical joke-teller who is unaffected by Parkinson's (and by extension any interlocutor involved in a conversation with others whose speech is considered "normal") may be undertaking the same mental processes to construct meaning, but as they have the advantage of being able to understand the teller's phonological stream on the first hearing, their processes would likely take place quickly and more privately. The audience may not be quite as involved in the negotiating of meaning that would expose how they arrived at an understanding.

My family's conversations, on the other hand, seem to display our meaning-making processes publicly. That is, when we have difficulty understanding, we must work these difficulties out with one another through a series of turns that appear to openly demonstrate the steps in our mental processing of communication. I thus align my theoretical approach to this data with linguistic researchers who view language not as a "hidden psychological process...but as a public sign system" (Goodwin, 2004, p. 166).

Statement of the Research Questions

In order to contribute to our knowledge of how humans use language as a medium for intersubjectivity, I adopt the following as my primary research question: How does my family come to understand a member who has almost entirely lost his ability to create distinguishable speech sounds, but who retains his cognitive ability and desire to discuss intellectually complex ideas? As a means of focusing this overarching research question and distilling the implications, I use the following questions as guides:

1. What strategies and processes does my family use to co-construct meaning with my father?
2. How does my family invoke different kinds of context to achieve meaning?
3. How do our family's meaning-making processes inform linguistic theories?
4. How can the insights gained in linguistics through this research improve the perception and treatment of individuals with disabilities in our society?

Before outlining in detail the specifics of the theoretical framework and methods I use to address these questions, I explicitly state the potential contributions of this research and provide a brief outline of the chapters in the dissertation.

Potential Contributions of the Research

The research conducted for this dissertation has the potential to inform theories in linguistics and to improve practical applications of this enhanced theoretical knowledge. Through this project, I work toward a new definition of the human capacity for language that is both more accurate in its portrayal and more useful than traditional linguistics. In this section, I first explain how my dissertation can add to our working knowledge of language. Next, I discuss how this research can be applied to improve our view on people with neurogenic speech

disorders. Finally, I suggest a new trajectory for speech language therapy for Parkinson's patients and their families.

Throughout this dissertation, I further the notion that the human language capacity only exists in so far as it is employed by speakers. This is in direct opposition to traditional lines of thought in theoretical linguistics that posit an underlying competence module in the brain of individual speakers that transmits messages to individual listeners through the machinery of syntax. As theoretical linguistic inquiry has increasingly focused on syntax as the primary engine for making utterances, language itself has often been equated with syntax and the study of language has often been assumed to be the study of the systematics of syntax (Lieberman, 2002).

By way of contrast, I situate this dissertation within linguistic approaches that view language as only one of many equally significant modes of communication. As I analyze the communication strategies of both a man who has lost his ability to make distinguishable speech sounds (the basis of syntax) and his family, I demonstrate that the primacy given to hierarchically organized speech sounds in theoretical linguistics is not well founded. As my family manages to communicate successfully without relying exclusively on the ability to parse words from my father's phonological stream, we provide evidence that the human language capacity is inextricably bound to other modes of communication, to physical and social contexts, and to the socially formed intersubjectivities we develop over many years of co-creating meaning within the same community of speakers (Ochs & Capps, 2001). The field of Linguistics as a whole can benefit from this newly expanded notion of language as the process of co-creating meaning.

By adopting the view that the human capacity for language is a process that is located within the interstices of human interaction rather than in a competence module in one person's

brain, we can begin to view my father and thousands in similar predicaments as competent and significant speakers. As I demonstrate throughout this dissertation the multiple ways in which my family manages to negotiate meaning, it is my hope that this study can contribute to a more humane paradigm where people with disabilities are viewed in terms of what they *do* accomplish rather than what they do not.

The concept of “co-creation” of meaning (Jacoby & Ochs, 1995) is essential to understanding that it is the community of speakers who know a Parkinson’s patient the best who serve as part of the patient’s ability. In caregiving literature and in recent work on aphasic family members, it is often noted that the voice of the caregiver can be lost as she or he works to help another speak (Goodwin, 2004). Analyzing my family’s interactions through the lens of co-construction highlights the devoted efforts of those who serve as speech partners and custodians of their loved ones’ language abilities. One of my aims in this research is to draw attention to the important and relentless work that caregivers do as (often sole) stewards of another’s ability to have meaningful interactions with the rest of the world.

Finally, this research has the potential to radically affect the field of Speech Language Pathology and the therapies practitioners employ. I believe strongly that the strategies that a particular family develops in order to manage communication should not die with them. These strategies can potentially inform more effective therapies for people with a wide range of speech disorders and can be particularly influential for people with Parkinson’s.

Currently, there are very few resources dedicated to speech therapy in Parkinson’s patients as compared with other disorders. While this is due to a number of factors, the essence of the problem is that Parkinson’s is a degenerative disease. Providing speech therapy for people with PD is limited as our present medical insurance system only pays for therapies that clearly

demonstrate marked and continued improvements in patients with PD. If we assess a patient's abilities based solely on his or her ability to produce context-removed utterances on language elicitation tests (which they may perceive to be irrelevant to their daily lives), we will always find a victim of a degenerative disease to be increasingly losing language skills. Such a person will be judged to be incapable of improvement or undeserving of therapeutic services because the measure of ability is poorly calibrated.

If we instead apply our knowledge about the human language ability discussed above to this condition, we find that speech therapy for this disorder in particular must be done as group or family therapy. That is, as we know that the language ability of a Parkinson's patient resides within the functional interactions he or she has with a close community of speakers, therapy must not focus on training a declining ability in one individual's head but should instead be geared toward teaching family members and close friends augmentative techniques that support and develop the voice of people who might otherwise be disabled. Rather than focusing on the limitations of people with speech disabilities, I suggest that therapy should concentrate on honing, enhancing, and encouraging the skills that communities of speakers surrounding the person with a disorder use daily to push the limits of what our capacity for human language is. Such an approach to therapy has the potential to increase the abilities of those with PD so that they may participate more fully in interactions.

Organization of the Dissertation

The next chapter (Chapter 2) of this dissertation is a review of literature on neurogenic speech disorders, with a specific goal of situating the current study in social-interactional research on PD. In Chapter 3, I discuss my family's history and my own academic experiences that have shaped this research. I provide narratives about my family in this chapter as a way of

introducing the research participants and topics examined in this dissertation. In Chapter 4, I outline the theoretical framework I use to interpret the data collected for this project. Also in Chapter 4, I describe the design of the project and the methods I used to collect and interpret the data.

Chapter 5 is the first findings chapter, where I discuss how my family uses gestures in a semiotically rich environment in order to co-construct meaning. Chapter 6 is the second findings chapter, where I discuss the concept of scaffolding and give examples of how my family uses this as a strategy to co-create meaning. Chapter 7 is the final findings chapter, where I demonstrate how my family relies on our history and shared family narratives in order to co-construct meaning. Chapter 8 is the conclusions chapter, where I summarize my findings and discuss the practical implications of this dissertation.

CHAPTER 2: LITERATURE REVIEW ON NEUROGENIC SPEECH DISORDERS

In this chapter I provide a brief review of research on the speech disorders associated with Parkinson's disease (PD), Alzheimer's Disease (AD), and stroke-induced aphasia. While the three diseases have varied pathologies and manifest different symptoms, there are parallel trends and related research among the three subfields that I later draw on to cross-pollinate my own research approach. I start with a summary of findings from the biomedical traditions and then move to the research focused on social-interactional aspects of the speech difficulties with the different disease.

Introduction to Parkinson's Disease and Associated Speech Disorders

Approximately four million people worldwide are estimated to have Parkinson's disease (Parkinson's Disease Society of the UK, 2008). In the United States, 60,000 new cases are diagnosed each year, adding to the estimated 1.5 million people in our country who are already living with the disease. Symptoms of the disease only appear in Parkinson's patients after about 80% of the dopamine-producing cells in the substantia nigra (a small region in the brain stem strongly implicated in motor movement) have already died, making it difficult for doctors to formulate preventive protocols. As dopamine is responsible for smooth motor control, the effects of losing the ability to produce this neurotransmitter can be devastating, limiting all types of motor movement (Parkinson's Disease Foundation, 2008).

While the more well known symptoms of Parkinson's Disease (PD) are the hand tremor, shuffle-stepping, impaired gross motor movement, and the eventual catatonic state, between 80 and 90% of people with PD also display the symptoms of speech and voice disorders (Letter,

Santens, & Van Borsel, 2005). Typically, Parkinson's patients develop hypokinetic dysarthria, which is characterized by poor volume control (hypophonia), hoarseness, monotone voice, slurred articulation, stuttered repetitions, abnormal speech rate, and frozen facial muscles (National Center for Voice and Speech, 2007). Recent research has also identified word-finding difficulties, defective prosodic abilities, and abnormal voice quality as part of the speech difficulties experienced by people with Parkinson's (Letter et al., 2005). The combination of all these deficits can lead to an overall loss of intelligibility (Goberman & Elmer, 2005). These speech difficulties cause frustrations and decreased overall quality of life for PD sufferers, their caregivers, and their family members (Fernandez, Tabamo, David, & Friedman, 2001; Thommessen, Aarsland, Braekhus, Oksengaard, Engedal, & Laake, 2002; Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999).

Biomedical Research on Parkinson's-Related Speech Disorders

Researchers concerned with the biomedical aspects of PD have made and continue to make important contributions to the study of speech in people with Parkinson's. The most basic research stemming from the biomedical tradition focuses on studying speech in people with PD in order to form increasingly accurate characterizations of the physical effects of the disease on speech (Miller, Noble, Jones, & Burn, 2006). In an effort to better understand the underlying processing mechanisms that are impaired in people with PD, for example, Arnott, Chenery, Murdoch, and Silburn, (2005) administered grammaticality judgment tests, sentence/picture matching tasks, probe questions, and morphosyntactic priming experiments. They found that the time period during which people with PD can access morphosyntactic information on-line is reduced. This study may help to explain investigators' qualitative reports of difficulties in comprehending complex sentences found in people with PD.

Corollary to this research on identifying characteristics of Parkinsonian speech is research that attempts to establish a relationship between the progression of the disease in general and intelligibility of speech. Miller, Allcock, Jones, Noble, Hildreth, and Burn, (2007). for example, had people unaccustomed to hearing dysarthric speech listen to patients in various stages of PD and then questioned their perceptions of the subjects' intelligibility. The Mini-Mental State Exam (MMSE) and the Unified Parkinson's Disease Rating Scale (UPDRS) were administered to the subjects with PD in order to determine what the researchers call, "objective measures" of the patients' cognitive and physical abilities (Miller et al., 2007, p.1189). The patients with PD themselves were also given questionnaires in order to determine how their own perceptions correlated with those who listened to their speech. The researchers concluded that while speech intelligibility is significantly reduced in people with PD, the loss of intelligibility does not correlate with stage of disease. Miller et al. (2007) also found that the patients' own perceptions of their intelligibility do not accord with the objective measures established in the standardized tests.

Researchers with similar interests in speech intelligibility attempt to find correlations between medications administered to control the symptoms of PD and dysarthric speech. Letter et al. (2005) found that while Levodopa, the synthetic replacement for the body's missing dopamine, has a positive effect on tongue strength and endurance (thereby aiding in speech production), over long periods of time, continued use of Levodopa actually exacerbates dysfluencies of speech. They also found that their subjects did not take efforts to correct themselves after producing unintelligible speech fragments. The authors interpret this as support for previous research that has proposed a defective auditory feedback mechanism in patients with PD.

Identifying the location of various speech tasks in the brain is yet another major focus of biomedical research on speech of patients with PD (Miller et al., 2006). In studying the reduced sensitivity to negative emotions, Dara, Monetta, and Pell (2008) found that people with PD had difficulty in appropriately categorizing and processing negative emotions such as anger, disgust and fear. From their study, they conclude that the basal ganglia, which is known to be affected by PD in general, may play a significant role in processing emotional speech prosody in all humans.

All of the above pursuits can be classified as research in pursuit of solidifying a knowledge base about the interactions between the brain, speech, and PD for its own sake. That is, most of the research reviewed above is aimed at identifying what the speech problems are in people with PD and how these problems are characterized neurologically. While this research certainly does build a very basic foundation for clinical and therapeutic applications, improving speech does not seem to be the main aim, nor does this research approach seem to have direct impact.

Clinical Applications of Biomedical Research for Parkinson's-Related Speech Disorders

Biomedical researchers specifically interested in developing clinical applications have also made significant contributions to our understanding and management of speech of patients suffering from PD. A vested interest in improving speech assessment in clinical settings has led to the development of the speech assessment section of the Unified Parkinson's Disease Rating Scale UPDRS for example. Within the Activities of Daily Life portion of the UPDRS, speech is only one of thirteen other skills that are measured on a scale of 0 to 4, with 0 equating to normal speech and 4 equaling unintelligible (UPDRS Organization, 2006).

Acoustic analysis of clear versus conversational speech has also been applied to the problem of speech in people with PD (Goberman & Elmer, 2005). Researchers here found that

when they asked people with PD to read passages with no explicit instructions, they performed poorly in terms of the acoustic measures they analyzed including articulation, fundamental frequency, and speed. When the researchers then asked their subjects to read passages after being asked to “Produce the items as clearly as possible, as if I am having trouble hearing or understanding you,” the subjects improved on all measures (Goberman & Elmer, 2005, p. 219). The authors conclude that their research has direct implications for clinical and treatment settings as people with PD can actually be trained to monitor their speech more carefully and to put forth more effort in order to ensure that they are understood. The authors also admit that a potential drawback of their conclusion may be that people with PD may not be able to transfer the skills from an experimental or clinical setting into daily conversations with any significant endurance.

The biomedical approach has also led to the only accepted and widely used treatment protocol for improving speech of people with PD, the Lee Silverman Voice Therapy (LSVT) (LSVT Organization, 2008). The LSVT focuses exclusively on improving phonation in people who have speech impairments due to PD through breathing exercises. While this does address hypophonia, known to be one of the major problems at the root of intelligibility in PD, no other aspects of speech are treated.

Only recently has research on speech of PD sufferers begun turning to analysis of the social effects of impaired speech and therapeutic recommendations at the social level. Charlton & Barrow (2002) suggest that, “Biomedical approaches have dominated research and practice in PD because drug treatment can offer relief from physical symptoms” (p. 472). While it is true that pharmaceutical treatment can prove effective for many of the motor movement impairments associated with PD, researchers have also shown (as mentioned above) that medications can actually hinder speech production when used over long periods of time (Letter et al., 2005). In

order to find better ways of understanding and managing speech in people with PD, many people have developed research that addresses the social and psychological aspects of the disease. I now turn to a review of this research on speech in PD that addresses the many social impacts of the disease with the goal of finding improved methods of treatment.

*Social-Interactional Studies in Speech in People with PD with Clinical
Implications*

There is a growing recognition that in order to provide the most useful therapy to those whose speech limitations impede their daily interaction, research must involve a shift toward analyzing the person with PD as he or she is embedded within the social matrix. Among researchers who study social interaction of families dealing with a member with PD, there is a common understanding that the need to “...move beyond acoustic, perceptual and physiological changes to speech, divorced from the speaker, the listener, and the communicative situation,” is vital (Miller et al., 2006, p.238). These researchers insist that while acoustic and perceptual (on behalf of both the speaker and interlocutor) changes to speech have been widely studied, “...little empirical evidence exists concerning the impact these [changes] have on their lives and coping strategies to deal with them” (Miller et al., 2006, p. 235). Recent research points out that “[a]lthough the medical model is well suited to acute illness, in chronic illness like PD, the long-term social and psychological effects have not been addressed adequately within it” (Charlton & Barrow, 2002, p. 472)

While there is still only sparse research that examines patients with PD within their social groups, this line of inquiry has the potential to change the landscape of both clinical assessment of language skills and implementation of therapy in Parkinson’s speech disorders. In a critique of work that focuses on speech characteristics in isolation from the people who use them, Dorothy

Robertson (2006) points out that, “[a]cademic research can sometimes lose sight of the human context, and the literature on speech in Parkinson’s disease has largely concentrated on detailed dissection and description of the various impairments” (p. 211). Whitworth, Lesser, and McKeith, (1999) suggest that this approach “ha[s] resulted in intervention being principally directed at maximizing use of the speech and voice apparatus in the context of the progressive nature of the disease” (p. 407). In addressing the problem with trying to improve usage of the speech and voice apparatus, Charlton & Barrow (2002) note that “because PD is progressive and incurable, the scope for using behavi[o]rally orientated coping methods (e.g. to counteract the condition) are limited” (p. 475). They further suggest that concentrating on the psychological impact of the speech disorders rather than trying to modify physiological effects would be more useful.

Similarly, Robertson (2006) expresses a concern that much of the research on Parkinson’s speech underestimates the non-verbal factors of communication. She references work by Pentland (1987) and Pitcairn (1990) that demonstrated how changes in speech due to this disease “have been shown to engender negative personality judgments of PD patients amongst health professional and are likely to similarly impact personal relationships” (Robertson, 2006, p. 211). In her recommendations for a more humane and inclusive analysis of language, she suggests that there is a “need to shift the research and therapeutic emphasis from the current focus on speech parameters to include cognitive, psychological, and physical aspects as well as the role of the strategies to facilitate and maintain communication” (Robertson, 2006, p. 211).

In a move toward this goal of reorienting to the human aspect of research, Miller and Allcock (2008) developed a study to examine how people with Parkinson’s perceive their own

communication problems. Using the UPDRS, the Mini-Mental Standard Exam (MMSE), the Geriatric Depression Scale (GDS), and a 60-item intelligibility test, Miller and Allcock (2008) collected clinical measures of their subjects' speech. They then used a questionnaire with a bipolar scale to assess both the subjects' own perceptions of their speech and the perceptions of their caregivers. They compared the responses to the questionnaires about perception of communication to the clinical measures to see how closely perceptions matched up with clinical measures. In general, they found that the subjects' own perceptions of how their speech had changed were more drastic than the clinical measures demonstrated. Their own perceptions of their speech difficulties were also more negative than the perceptions of their caregivers. The authors conclude that the psychosocial barriers perceived by people with Parkinson's can be a greater impediment to adjustments to and management of the disease than "frank impairment changes," as the patients may become withdrawn socially well before their interlocutors would notice the effects of the deterioration of their speech (Miller & Allcock, 2008, p. 20).

Implications of this research for clinical management include the notion that caregivers may not fully appreciate the struggle of their impaired partners and that people with Parkinson's should be referred to speech therapy that directly involves their partner before their potential speech impairments are clinically measurable. In this way, patients may learn coping strategies together before developing feelings of loss of control and confidence that could in turn become significant psychosocial barriers to speech. The authors further suggest therapy that is geared toward "maintaining and re-establishing control and independence, seeking ways alone or in partnership with the listener of conveying messages clearly without frustrating hurdles..." (Miller & Allcock, 2008, p. 20).

In research that yielded similar conclusions, Miller et al. (2006) conducted interviews in the homes of people with Parkinson's to further understandings of how speech impairments affected self-concept, family participation, and family dynamics. They take as a point of departure the question of whether or not the purpose of research in speech science studies coincides with the concerns of individuals with PD. They pose the question of whether the elements of oral change can actually "...be understood purely in terms of voice and speech parameters?" (Miller et al., 2006, p. 235).

In attempting to answer these questions, the researchers found that their subjects were concerned about their loss of intelligibility, which they conceived of as, "mumbling, tight mouth, slowness of speech, loss of clarity, and effort required to maintain intelligible speech" (Miller et al., 2006, p. 236). Subjects further reported that "freezing and day-to-day variability could be bothersome and demoralizing" (p. 236).

In their reports of interaction with others, some of the subjects with Parkinson's noted that they felt their listeners "lacked an appreciation of the difficulties they were facing in talking, talked over them, talked for them, did not wait for an answer, ignored them, or assumed they were stupid" (Miller et al., 2006, p. 237). The authors include several quotes from respondents who comment on how it feels to converse despite the limitations of Parkinson's: "By the time you've finished, the subject has changed and they haven't waited for your answer to come out" (p. 237). The authors indicate that those who report negative interactions in conversation can become depressed, resigned and withdrawn from interaction altogether: "...embarrassed, people just keep staring at you when you cannot get your words out...so I just avoid people" (p. 237). In contrast, other subjects responding in this same category of "interaction with others" gave more positive accounts. For example, one subject said that he did "feel supported by others

accepting differences, giving choice, negotiating how to make conversations easier, helping them to laugh about things” (p. 237).

During a different part of the interviews, Miller et al. (2006) question their subjects on coping strategies. They found four major strategies that they identified as: “Physical strategies, monitoring and adjusting strategies, managing conversations, [and] helping others to understand” (p. 237). The authors report that the particular type of coping strategy subjects and their partners used were based on their physical and affective state at the moment of interaction and other social factors such as the differential status of the speakers and both the real and perceived reactions of interlocutors.

In conclusion, Miller et al. (2006) suggest early referral to speech therapy that (crucially) involves speech partners. They suggest this may prevent the development of “maladaptive coping strategies and feelings of frustration that may well have cornered a speaker into withdrawal, isolation, and family tensions, militating against full socialization and participation” (p. 238).

In analysis of American Sign Language (ASL) communication between deaf speakers among whom at least one conversational partner has Parkinson’s disease, Kegl and Poizner (1998) focus specifically on the shift of burden for the work in conversation to the non-Parkinson’s interlocutor. Focusing on those who converse with deaf signers with Parkinson’s, the authors note that, “[a]nalysis of language in context must take into account not only grammatical context on the part of the producers of language output but also the viability of the message as received by the interlocutor” (Kegl & Poizner, 1998, p. 137). They claim that it is through studying the behavior of interlocutors who are not neurologically impaired that they gain access to a better understanding of the deficit of the impaired language producer.

Kegl & Poizner (1998) found that the signers affected by Parkinson's produced "systematically lax and reduced signs," that favored ease of articulation over ease of interpretation (p. 141). Their signs were characterized by "...an overall laxing of handshape movement, orientation, and place of articulation distinctions such that each handshape is only minimally distinguishable from others" (p. 140).² The signers with PD (consciously or not) placed a greater conversational burden for perception of communication on their interlocutors who compensated by reconstructing the discourse produced by those with PD and then verifying that they had understood correctly. Overall, the interlocutors to the PD signers were observed to give "...patient attentiveness to the PD signers' every move, taking over in many cases responsibility for clarifying or amplifying the PD signers' minimally signaled turn-taking claims, register[ing] sensitivity to their deficits..." (p. 151).

In keeping with research that underscores the importance of studying the social situations of people with Parkinson's, Kegl & Poizner (1998) conclude that,

In contrast with the individualized nature of sentence production and interpretation, the pragmatic aspects of conversation are a mutually negotiated operation. When one participant is not fully up to the task, the situation demands compensation from the remaining members of the conversation. (p. 151)

In an attempt to further understandings of the role of the interlocutor in speech with people with Parkinson's, Whitworth et al. (1999) adopted the Conversation Analysis Profile for People with Cognitive Impairment (CAPPCI) developed by Whitworth, Perkins, and Lesser (1997) and applied relevant categories to conversations between people with cognitive

² It is interesting to note here that the difficulty in making distinguishable hand signs is qualitatively similar to the slurred articulation of speech sounds, perhaps suggesting that control over both speech articulators and more gross motor movements are controlled in similar ways neurologically.

impairments that accompany Parkinson's and their "conversation partner." They define "conversation partner" as "the person or persons who has the most contact in communication situations with the person with cognitive impairment" (Whitworth et al., 1999, p. 410). They further specify that the conversation partner "may be a spouse, close family member, friend, or in some cases a professional carer" (p. 410).

The areas of inquiry the researchers used from the CAPPCI to profile speech in subjects with cognitive impairment and Parkinson's include: "initiation and turn taking, topic management, repair, memory and attention, linguistic abilities, articulation and prosody, [and] fluctuations (changes over the day or week)" (Whitworth et al., 1999, p. 411). In order to collect information on conversations with this population, the researchers did both a structured interview to gain information about caregivers' perceptions of what happens during conversation and then recorded one hour of conversation between the people with Parkinson's and their conversation partners. They then extracted ten minutes of conversation from the hour of recording for close analysis.³ During the analysis, the researchers used the categories of conversation from the CAPPCI mentioned above in order to create a profile of how conversational interactions took place. They then compared the interview data with the CAPPCI data.

Whitworth et al. (1999) found that the conversation partners developed five strategies in order to converse with their cognitively impaired partners. The strategies identified through the research are: "facilitatory," "confrontational," "acceptance," "avoidance," and "emotive response," (pp. 418-419). Of these, facilitatory made up 59.2% of the strategies identified, with

³ Whitworth et al. (1999) note the drawback of collecting such small samples of conversation. In particular, they point out that problems identified by conversation partners in the structured interview portion of their data collection were not observed in the hour of conversational data, making it difficult to draw conclusions between the caregivers' perceptions against the conversational pattern.

acceptance being used 22% of the time and confrontational 12.6% of the time. The researchers defined the facilitatory strategy as “problem solving in which the carer was actively engaged in managing the interaction to facilitate effective interaction” (p. 418). Actions that fall under this definition include encouraging new topics when the person with PD is stuck or at a loss for words, or encouraging topic maintenance by ushering conversations toward topics the person with PD is familiar or comfortable with. Confrontational strategies, the researchers note, commonly led to withdrawal by the person with PD and were characterized by such metadiscursive commentary or questions as, “let me have my say,” or “do you know what I’ve said?” (p. 418). Acceptance strategies were defined as showing a total acceptance of the actions of the person with PD rather than problem solving. In this category of action, no attempts were made by conversation partners to pick up previous threads of conversation to finish them or to confront issues. Rather, the conversation partner followed the lead of those with the cognitive impairment.

Within the most common category of strategies, “facilitatory,” the researchers found more specific ways in which conversation partners worked to maintain conversations. These include: provision of target output (providing words or sentences for the person with PD), increased time (waiting during conversational pauses), use of additional modalities, repeated, slowed, altered, or additional input, direct encouragements, explanatory strategies, recommendations to alter physical attributes (encouraging the person with PD to take expanded breaths of air or to increase the mouth opening), and other strategies such as maintaining eye contact during pauses.

Whitworth et al. (1999) conclude that the preponderance of facilitatory strategies suggests that caregivers are highly sensitive to “modifying both input and output during

conversation,” which they state has “implications for working with carers” (p. 422). In comparing the profiles created through the CAPPSCI to the interview data, they found that the caregivers who were the most aware of their partners’ problems in communication also used the greatest amount of alternative communication strategies. This suggests that therapy that focuses on making conversation partners aware of the particulars of the communication breakdowns would be useful in and of itself. Also, they demonstrate that there are additional impairments involved in Parkinson’s disease other than the articulatory and prosodic difficulties that are identified through other research approaches. By using Conversation Analysis with a clinical approach, they were able to identify problems at the level of conversational interaction in initiation, turn taking, word-finding, and topic management skills. They emphasize that, “The carers’ responses (or absence of them) were shown constantly to shape the course of interaction” (Whitworth et al., p. 422).

A lone journal article focused exclusively on practice of speech therapy based mostly on a nurse’s intuitions about what her patients need is entitled, “Improving Speech in Parkinson’s disease” and appears in the *Journal of Nursing* in 1973. Elizabeth Erb decided to start a speech class in a retirement home where she worked to give her clients “whatever help we could” (Erb, 1973, p. 1910). At the beginning of the article, Erb describes some of her patients, including a college professor who has written several books and a retired junior high school teacher who “speaks in such low tones he can hardly be understood” (p. 1910). Even though his intellect remains unaffected, Erb says he just sits in his chair all day long, only speaking when he calls to the nurse on occasion to reposition him in the chair.

Erb explains how she and a group of nurses at the home adapted exercises they had seen a speech therapist in the locals schools use for their own needs. A trained physiotherapist helped

them to set up their class and checked in on their progress routinely. Erb describes the speech exercise routine which starts out with upper-body and breathing exercises and then moves into exercises of the tongue, jaw and lip where the clients observe their movements in hand-held mirrors. She explains her technique for improving pronunciation where the clients go through the alphabet and pick out the letters that hamper their speech the most and then develop tongue twisters that specifically target these problems sounds. During some sessions, she selected excerpts of poetry or prose and copies the selections onto the chalkboard as a way of practicing careful speech together. Erb (1973) says that, “As we read these we try to give each word its own beauty and meaning so as to break the habit of running them together into one unintelligible utterance” (p. 1910). It would seem that in the early seventies, without acoustic and prosodic measures of speech nor abilities to assess phonation, this nurse was able to use her own clinical experience to improve areas of difficulty including the noticeable slurring together of words.

Each class, Erb works on applying these practiced techniques of speech improvement in conversation. Quite simply, she states, “we talk together” (p. 1911). The students talk about outings with family members, TV programs, or other topics of interest. Sometimes the entire class period is taken up with conversation. Erb claims the “conversation days are morale-boosters when the class is weary and frustrated by exercises” (p. 1911). Although Erb and her fellow nurses have no way of measuring their patients’ progress, she does include quotes from people who noticed significant changes in the students’ speech. About the retired college professor, the home’s administrator asks, “What have you done with Joe? The other day he was in my office and I could understand him” (p. 1911). Several weeks later, a visitor to the retired high school teacher noted, “Other times I couldn’t understand him but tonight I could understand everything he said” (p. 1911).

While Erb (1973) appreciates these positive responses, she also admits that it took several weeks to achieve just a few compliments. She points out that, “Any number of factors affect their speech: a poor night’s sleep, arthritic pain, an emotional upset before class” (p. 1911). While Erb reports that all the clients enjoy the class for different reasons, she establishes her goal thusly: “As we work with them, we try to give each one a sense of worth as a person and thus make their lives more enjoyable” (p. 1911). Although Erb and her colleagues did not rely on therapy protocols that were research based, they seemed able to apply accepted general speech therapy techniques successfully to a new situation. Rather than being interested in furthering clinical research, these nurses were interested in practice that was guided by their own intuitions and relationships with the particular people they knew well and helped on a daily basis.

Although Erb and her fellow nurses decided to administer therapy to clients without basing their exercises on detailed research, they do feel they had a significant impact on their patients’ lives. As mentioned in the section on biomedical research, at present, the only accepted speech therapy protocol that exists for Parkinson’s is the Lee Silverman Voice Treatment (LSVT), which focuses specifically and exclusively on increasing vocal loudness (LSVT Foundation, 2007). This lack of standardized therapy, combined with explicit calls for more interactional therapy provide an area for future researchers to improve upon.

Although some researchers do recognize the need for more work on assessment measures that analyze the social ramifications of PD, many of the studies that look at these social aspects gather data through questionnaires. While finding out how individuals feel about their changing communication skills through questionnaires is a worthy approach, Miller and Allcock (2008) point out that the predetermined question set by clinicians or researchers may not be adequate for accessing the true problems of the speakers as the questions are still focused on a standardized

set of researchers' concerns. This suggests that there is also a need for different research approaches that may more closely access the needs of the people with Parkinson's-related speech disorders. My own aims for filling in this gap in research will be discussed fully in the section entitled, *Addressing the Gaps in the Literature Through this Dissertation*.

Social-Interactional Research on Other Neurogenic Speech Disorders

Research on Alzheimer's

Recognizing the importance of assessing the abilities of those with neurogenic speech disorders through observations of genuine daily conversations is a common theme in literature concerning disorders with varied neurological causes. In studies of deteriorating speech in Alzheimer's disease, researchers have used discourse analysis (DA) and conversation analysis (CA) to examine patients' speech.

In explaining her rationale for looking at speech in Alzheimer's at the level of naturally-occurring discourse, Heidi Hamilton (1999) states that the researcher is able to examine the speech of elderly individuals

with the person they have chosen to talk with in everyday situations that are meaningful to them as contrasted with interactions such as the tests, interviews, and conversation which usually take place outside the normal stream of life for these individuals.

(Hamilton, 1999, p. 11)

In her critique of interviews that are used as measures of speech ability, she points out that the participant roles and division of labor in conversations in interview settings tend to be clear-cut: "The interviewer is usually understood to be in charge of asking the questions while the interviewee is expected to answer those questions" (p. 10). Her belief is that this type of

format is not useful for finding out anything about how participants would interact in real-life situations.

In her analysis of accommodation and mental disability, Hamilton analyzed fourteen naturally occurring conversations with Alzheimer's patients, schizophrenics, and the "mentally retarded" (Hamilton, 1991, p. 161). Hamilton found that speakers in all three of the populations studied were not able to take on the role of the other during conversational action. She defines this inability as "...hav[ing] difficulty in designing utterances in such a way that their conversational partners can understand what they are saying" (Hamilton, 1991, p. 161). In noticing a lack of pauses in conversations, she notes that the affected individuals do not pause to ensure their interlocutors are following them. The general conclusion Hamilton draws is that the impaired speakers force their interlocutors to "...do whatever work is necessary to make sense of what was just said" (Hamilton, 1991, p. 164).

In a study on clarification requests, Hamilton (1994) examined how interlocutors and patients with Alzheimer's manage comprehension difficulties. Her findings show that the interlocutors developed a hybrid strategy together, alternating between avoidance and correction during times of misunderstanding. In general, the non-Alzheimer's interlocutor allowed the person with Alzheimer's to continue the conversation until she had followed it to its natural end before the interlocutor would go back and ask for specific corrections.

Watson, Chenery, and Carter (1999) had similar findings when using Conversation Analysis to study trouble and repair in people with dementia and Alzheimer's. They found that the non-affected partners assumed more of the burden of signaling and repairing when there were communication difficulties. The authors suggest that the non-Alzheimer's interlocutors accepted dysfluencies and continued the conversation as a way of preserving the self-esteem of those with

Alzheimer's. The specific mechanisms non-Alzheimer's interlocutors used were paraphrasing, "hypothesis formation," and "requests for specific information" (p. 213).

While the above research all emphasizes that the impaired subjects demonstrated the ability to function in conversations yet would likely (or had actually) performed poorly on language assessment tests of different genres, this research does not take as its primary motivation the development of therapeutic means to helping the population of Alzheimer's communicators. In an effort to develop strategies to aid both sufferers from Alzheimer's and their caregivers, Steven Sabat (1999) analyzed the use of indirect repair in conversations with Alzheimer's patients. In his analysis of discourse between non-impaired individuals and individuals with Alzheimer's, Sabat found that the non-impaired conversationalists displayed a "cooperative attitude," "accommodation," and used "indirect repair," without which the "afflicted person's speech could easily have been seen as disjointed, rambling, stilted, and confused" (Sabat, 1999, p. 117).

Sabat draws the conclusion that his impaired subjects had not actually lost the ability to engage in dialogue competently, despite their performance on standardized tests in experimental settings where "... they showed marked deficiencies in all linguistic components such as syntax, semantics, and phonology in all modalities (reading, writing, aural comprehension and spoken production" (Sabat, 1999, p. 116). In terms of clinical applications of these research findings, Sabat suggests that it is the duty of researchers to change the way we treat our impaired conversation partners. In this study, his subjects' conversational success relied on the cooperation and accommodation of their interlocutors. He concludes by saying that "...we can position the person as incompetent and treat the person accordingly, or we can assume a degree of understanding and act accordingly" (p. 129).

Within the literature on speech in Alzheimer's there are several researchers who are analyzing impaired individuals' speech at the discourse level. They use both discourse analysis and conversation analysis in order to provide better means of assessment and suggestions for therapy. It is interesting to note how the particular pathology of Alzheimer's affects the types of conversational interactions that occur. Alzheimer's disease is characterized by a gradual deterioration of memory, language, and perception with accompanying "change[s] in personality, loss of reasoning capacity, difficulty in maintaining attention, orientation, and learning" (Hamilton, 1994, p. 6). The memory, language, and attention deficits in particular often change one of the major conversational goals from collaboratively working toward intersubjectivity to "saving face" (p.5). Rather than working to repair seemingly nonsensical utterances, the person speaking with an individual with Alzheimer's is likely to become involved in what Edgerton (1967) calls a "benevolent conspiracy," wherein incessant repairs, repeats, and reformulations on behalf of the non-impaired individual may actually serve to highlight the *incompetence* of the person with Alzheimer's. Although an interlocutor may have intentions of helping the person with Alzheimer's the effect can sometimes be detrimental. Nonetheless, in conversations with people with Alzheimer's the strategies of avoidance (Hamilton, 1994), accommodation, cooperation, and indirect repair (Sabat, 1999) thus figure prominently, as the purpose is often maintaining an ongoing discourse rather than co-constructing an intended and sensible meaning.

In the next section, I turn to an examination of research on aphasias caused by stroke. Although the pathology of Alzheimer's and stroke-induced aphasias are different, researchers use focusing on speech in people who have suffered strokes are also interested in studying the interactional mechanisms of interlocutors are reviewed.

Research on Aphasia (Stroke-Induced and Other)

The most comprehensive body of literature that treats conversation with neurologically impaired speech-disordered populations is in the area of aphasia, most of which is stroke-induced. The vast amount of research on stroke-induced disorders as compared with other neurological speech disorders is likely due to a combination of different reasons including the high number of people who suffer from strokes. In the US, an estimated 700,000 per year suffer strokes (National Stroke Association, 2008). Additionally, stroke is not a degenerative disorder like Alzheimer's and Parkinson's diseases: stroke victims can often recover much of their abilities, mostly within the first six months after the attack. Finding ways to help patients recover or improve their speech is both more feasible and better explored than the other neurogenic disorders examined here.

As with Parkinson's disease, there is a tremendous amount of research in stroke dedicated to locating specific areas in the brain that are responsible for particular functions (Goodwin, 2003). Assessments of language skills in clinical settings is still predominately geared toward gathering context-free utterances as a way of pairing information from Computerized Tomography (CT) scans and Magnetic Resonance Imaging (MRI) with data about linguistic deficits. The determinations of what parts of the brain have been affected by stroke that come from this combination of information then serves as a basis for therapeutic protocols in patients.

In contrast to this biomedical approach to clinical applications, many researchers have begun to study conversational interaction with the aim of more accurately representing patients' language abilities and developing clinical protocols that enhance these abilities rather than focusing on their deficits. Pointing out the flaws with using stroke patients to define the different areas of the brain that are assigned to particular tasks in language, Schegloff (2003) criticizes the

labeling of patients as being either “Broca’s Aphasics” (having impaired language production) or “Wernicke’s Aphasics” (displaying impaired language comprehension) (p. 44). His critique is based on the notion that when speech professionals label their patients in these ways, they create social categories that then limit “what they could be up to” (p. 44). In his view, once a person is labeled as aphasic, they cannot be anything else but aphasics. Instead, Schegloff suggests looking at these individuals while they are going about their daily activities so that we can see “who and what they are doing the being of” rather than seeing them as limited social actors (Schegloff, 2003, p. 44).

As Schegloff uses Applied CA to examine the interactions of individuals with a severed corpus callosum, he discovers that discorsal features of language in interaction such as timing, phrasing, prosody and even politeness do not seem to be separate in the brain from the organization of syntax. This research is both motivated by and confirms his “...skepticism about the unilateral location for the pragmatic and discourse organizational components of language based in large measure on ‘testing’ of various sorts” (Schegloff, 2003, p. 25).

This opposition to using tests on stroke patients to localize brain functions is echoed throughout the work of Charles Goodwin (1995, 2000, 2002, 2003a). Goodwin provides an “alternative geography of cognition” in general, that is, a “reflexively situated process that encompasses both the sign-making capacity of the individual, for example through the production of talk” (Goodwin, 2000, p. 1490). Integral to Goodwin’s understanding of language is this stated notion that language is a process that can only be studied by watching it unfold in a social matrix rather than accessed through any kind of test or experimental measure of a language ability that resides in the brain. Goodwin suggests expanding the analytic frame to include “embodied speakers” (Goodwin, 2003b, p. 26) who use every semiotic resource

available in their semiotically rich environment and semiotically significant bodies to make themselves understood (Goodwin, 2003b, c).

In order to explore the processes that are language, a growing number of researchers are turning to Applied Conversation Analysis to study conversations with people with neurogenic language disorders (Watson et al., 1999). This trend is particularly strong within the literature on aphasia. As conversations with impaired individuals are often troubled by misunderstandings and other comprehension difficulties, the mechanisms identified and described in early CA literature on how interlocutors manage communication breakdowns are drawn on as useful tools for exploring how these same processes play out in conversations with impaired populations. Watson et al. (1999) explain the utility of CA stating that it allows analysts to see how difficulty in conversation “is signaled, how it is repaired, and to what extent these conversational repairs are successful” (Watson et al., 1999, p. 195).

In applying the CA concept of repair to conversations with aphasics, Laasko (2003) found that when the non-aphasic interlocutors failed to initiate repairs, aphasics were saddled with added burden of having to produce the further talk needed to work their way out of repair sequences. Laasko found this process worked differently if the interlocutor was a spouse or a therapist: spouses tended to fill in missing lexical items, which led to shorter repair sequences, while therapists frequently just let the aphasic manage repair on his or her own. Laasko notes that this may be due to the training and intentions of the therapists who are specifically trying to get the aphasic to do the work alone so that they may assess their lone abilities. Alternately, he proposes that the therapists may not have enough contextual knowledge about the world of their clients to be able to know what lexical items the aphasic needs.

Similarly, Oelschlaeger and Damico (2000) demonstrate that people with aphasia can be competent social actors when their spouses work along with them to find missing words during word searches. They use CA to analyze the conversations between an aphasic man and his wife who waits for him to search for his words on his own and then only enters into the word search when he signals that he needs help. As she offers candidate solutions to his word-finding puzzles, she does so with a rising intonation, indicating that she is not sure of her offering and that she needs him to ratify what she has provided. In this way, they work together to constitute the aphasic man as a significant and capable interactant.

In their study of how laughter is used by aphasics to achieve conversational goals, Madden, Oelschlaeger, and Damico (2002) find that laughter serves to “smooth out potential social impropriety” (p. 1206) and also serves a “compensatory function” (p. 1209). Madden et al. (2002) state that even though they consider laughter to be a non-linguistic behavior, individuals with aphasia use it in purposeful ways to contribute to meaning-making in conversations.

In applying CA to the study of turn taking in people with aphasia, Wilkinson, Beeke, and Maxim (2003) find that aphasics use creative word orders, often fronting the words that carry the most meaning content. The researchers find that interlocutors of people with aphasia are able to understand their partners’ utterances regardless of the anomalous word order. The authors interpret this to mean that syntax may not be as important to meaning-making as previously thought. Wilkinson et al. (2003) suggest a definition of language as “adaptation to the environment” (p. 60) which implies that aphasic speakers are actually very capable users of language who adapt to their limitations in creative ways.

Building on Goffman’s (1964) work on physical handicap and disfigurement, Schegloff (2003) argues for applying CA to conversations with people with disabilities as a way of adding

to the canon of CA research. Schegloff reminds readers that Goffman viewed interactions with these “special populations” as informative sites for understanding problems that all people encounter. To illustrate, Schegloff points out that all people experience (to some degree) “problems of the management of appearance and of information, the contingencies of being discredited and discreditable, with the full moral weight carried by those terms” (Schegloff, 2003, p. 23). As Schegloff studies interactions with two people with severe speech impairment due to a severed corpus callosum that would otherwise unify the two hemispheres of the brain, he approaches analysis of their conversations in the same way that he would non-affected individuals. In this way, Schegloff allows the actions of these two research subjects to define what they are doing rather than allowing pre-determined notions of their disabilities to assess their impairments. The main thrust of this paper lies in Schegloff’s suggestions and examples of how to do analysis on interaction with and among impaired individuals. He recommends bringing the resources from CA to bear on problematized talk not just as a means of finding out how disordered speech gets done, but in order to find commonalities with speech in non-disordered individual and thereby better inform research on human interaction in general while also adding to the store of CA resources.

While Schegloff’s work on speech disorders has implications for all practitioners of CA, other work that applies CA to speech disorders carries direct implications for practitioners in speech therapy. In outlining their research aims, Ramsberger and Lise (2003) overtly critique therapy that is guided by the medical model stating, “In this approach, rehabilitation emphasis is placed on the person with aphasia, and the desired outcome is a ‘cure’ of symptoms of aphasia, to the extent possible” (p. 283). The authors do not completely deny the utility of the medical approach but rather draw a distinction between the times when a medical or alternative approach

might be most useful. Ramsberger & Lise (2003) Charlton and Barrow's claims (2002) about the appropriateness of the medical orientation in acute stages of an illness, and point out that in stroke in particular, most of the recovery of linguistic functioning takes place during the first few weeks after the stroke. They then assert that, "when significant improvement of aphasia symptoms can no longer be demonstrated, the medical perspective loses its relevance for further rehabilitation efforts" (p. 283).

Providing extended and comprehensive analyses of his own father who suffered and survived a stroke, Charles Goodwin, through publications that span several decades, addresses the need for therapies that do more than simply assess and attempt to treat a single individual's language skills. Over a period of eight years, Goodwin recorded his severely affected father in conversations with family members that occurred mostly in their own home. Goodwin's collection of data has resulted in approximately 210 hours of videotaped interaction (Goodwin, 2004). Although his father, Chil, had a successful career as an attorney in New York, his stroke reduced his lexical repertoire to the three words, "Yes," "No," and "and," (p. 152). While Chil would appear to most to be an extremely limited social actor, he in fact participated as a competent interactant thanks to his family's abilities and willingness to develop communication strategies that allowed him to express complex ideas. Chil's linguistic abilities, according to Goodwin, were not lodged within his own head or body, but were located in the interstices between many actors, participating within semiotically rich environments (Goodwin, 2003b). Before discussing the radical implications of Goodwin's research for speech therapy and for the treatment of individuals generally perceived to be disabled, I will briefly give the highlights of his work that led to his conclusions about how best to help stroke patients recover their abilities to participate meaningfully in conversations.

In his work on gesture (1995, 1996, 2000, 2002, 2004), Goodwin demonstrates how Chil is able to embed hand motions within the ongoing talk of others to make meaning. When Chil's family is making plans for dinner, Chil holds up his hand, with five fingers. At first Chil's daughter Pat believes he is referring to a recommendation of a time to go to dinner: five o'clock. Over several turns, the family is eventually able to figure out that Chil is trying to give his opinion on who to invite to the dinner. His gesture represents a number of people who should come. By waiting for the appropriate time within others' talk to contribute his gesture, Chil is able to participate as a competent social actor (Goodwin, 2002, 2003a, c).

Chil is able to use gesture in combination with intonation, sequential placement, and facial expressions deployed in physical spaces that themselves are meaningful in order to make himself understood. Chil's actions do not just directly and opaquely point to a referent such as we would see when an individual, perhaps a child, is pointing at an object she or he wants. Instead, he is able to communicate about sophisticated and complex ideas; he is even able to participate in telling stories about events that occurred fifty years in the past (Goodwin, 2004). Yet how can he do this with only the ability to use three words and a series of nonsense syllables variously ordered for different meanings (e.g. duh duh duh duh duh) (Goodwin, 2002, 2003a, c).

In Goodwin's analysis of Chil's interactions, we see several occurrences where Chil uses gesture to direct other people to take complex actions. For example, Chil draws an arc in the air with his arm and outstretched fingers in order to prescribe a proposed vector of action for his family member, Chuck. Keeping one hand anchored as it points out the window to the driveway, he then draws an arc with his other hand from the anchor point that extends to the front door, then down the hallway and to the kitchen. As the family has just returned from a trip to the grocery store, Chuck is able to read that Chil is asking for the groceries to be brought in through

a certain door. Here, Chil is not only explaining a complex action, he is actually directing others to perform a chore (Goodwin, 2002, 2003a, c).

When shopping for electrical wiring for the house, Chil and Chuck go to a large home improvement store (Goodwin, 2006). As they are in the aisle facing a selection of wires, Chil begins pointing in front of him and then behind him. While at first Chuck interprets this gesture as pointing to objects in their immediate surrounds, he eventually figures out that Chil is making a more symbolic reference to the “the front and back of the house,” both places for which they will need to buy wiring. Goodwin calls this “transposed space,” where an interactant is in some sense “pointing” to an area that is different from the one in which they are currently situated.

As Chuck and Chil are sitting at the kitchen table discussing proposed events for the day, Chuck suggests going for a drive (Goodwin, 2006). While Chil agrees this is a good idea, as Chuck proposes a particular drive, “up along the river,” Chil uses intonation and prosody to color a string of nonsense syllables in order to let Chuck know he would prefer to go somewhere else for a drive. Chil then places both his arms in the air, using one hand as an anchoring point and drawing a particular arc with his other arm to indicate a spatial difference and direction that Chuck can interpret as a park up the river called “Bear Mountain.”

At the kitchen table, Chil’s daughter-in-law asks him if he has ever experienced an earthquake (Goodwin, 2004). After Chil’s wife tells her own story about being in an earthquake, Chil utters the syllables, “yeah, duh duh duh duh duh,” with particular and meaningful intonational and prosodic contours that indicate he is soliciting his wife’s attention and help. Chil then draws out the shape of a rectangle in the air and then points, indicating some object over someone’s head. From this, Chil’s wife is able to interpret that Chil wants to tell the story about an earthquake they experienced fifty years previous, where a picture that was hanging above

their son's crib shook on the wall, threatening to fall on him. Chil and his wife then build the story together as they tell it, Chil's wife using a series of guesses to propose potential aspects of the story Chil may want her to talk about.

Correct interpretations of Chil's gestures and vocal contributions rely on others who know him well to do quite a bit of guessing and negotiating. As they realize that he is an active and intentional actor, they can read his placements of utterances and actions within ongoing talk or action as consequential. The family is also familiar with the same physical spaces as Chil, which allows them to understand particular movements he makes toward objects or spaces (as in the case of the grocery task). Although Chil has almost no linguistic repertoire at all, he is able to texture the few words and syllables that he does have with changes in intonation and prosody in order to make meaning. As Chil has shared his life with his family for many decades, his family also serves as a repository of memories on which they can draw during conversations in order to co-tell stories with him.

In his 2004 article entitled, *A competent speaker who can't speak: The social life of aphasia*, Goodwin explains some of his motivations for carrying out his line of research: "...I believed that documenting what he was able to accomplish might help to change the way in which people with severe brain damage and impaired language abilities are frequently stigmatized as cognitively impaired, less-than-normal human beings" (Goodwin, 2004, p. 157). This desire to change perceptions of the abilities of those considered to be disabled resounds throughout Goodwin's work. By showing how Chil creatively expands his own meaning-making abilities and those of his family, Goodwin positions Chil and others with neurogenic speech disorders as not only competent, but as perhaps even more talented than those who have not been trained in alternative communication strategies through years of struggling to communicate

under such severe circumstances. Goodwin pursued this research with the recognition that Chil demonstrated “communicative abilities that were well beyond those described by his doctors (one of whom predicted that he would spend the rest of his life essentially as a vegetable)” (p. 156). As Goodwin is a linguistic anthropologist rather than a speech language pathologist, he draws linguistic conclusions with ethical or moral suggestions for approaches to therapy rather than recommending specific techniques to rehabilitate lost abilities. In a powerful illustration of how viewing people with brain damage as competent has moral imperatives for caregivers, doctors, and therapists, he recounts a painful incident in which Chil was treated as incompetent. While a group of doctors were inserting a catheter in Chil in the hospital after the stroke, Chil was trying to communicate his physical pain and objection to their actions. The doctors continued to insert Chil’s catheter incorrectly and Goodwin suggests they may have counted his utterances as only “...the ravings of a man who’d just suffered a stroke and didn’t know what he was doing” (Goodwin, 1995, p. 25). Goodwin implies that if we begin to see all people as competent and work with them to help them make the meanings that are relevant to them, they will be treated as full human actors, with all the basic rights that accompany being human.

Central also to Goodwin’s clinical recommendations is the idea that the unit of linguistic competence must be expanded to include a disabled interlocutor’s community of speakers rather than drawing an “analytic boundary” at the “skin of the participants” (Goodwin, 2003b, p. 11). A result of viewing linguistic abilities as residing solely within an individual’s head, Goodwin points out that the communication strategies that stroke patients and their families create “develops within thousands of small, isolated pockets, and the special adaptations each family creates die with the person who suffered the stroke” (Goodwin, 2003a, p. 108). In Chil’s case, Goodwin notes that his abilities to communicate about so many things in his past died with his

wife who knew his past intimately. As a potential solution to this loss of ability with loss of life, Goodwin suggests, “Intervention directed at partner behaviour is as important as any remediation targeting underlying impairments” (Goodwin, 2004, p. 155). The implications of Goodwin’s work are that therapy should focus on codifying the mechanisms through which people with limited means manage to work in concert with others to co-construct meaning. Goodwin’s body of research goes a long way toward this goal.

Areas for Advancement of Research on Neurogenic Speech Disorders

Summary of the Literature on Speech in PD

While researchers in the biomedical tradition have extensively documented the physical difficulties associated with speech in PD, this approach to speech study has not yielded abundant information about the real-life struggles of communication. The biomedical approach has served as the basis for the development of some assessment protocols of speech ability (such as the speech portion of the UPDRS). From this approach, the assessment of a patient’s speech is viewed as a way of determining what overall stage in the disease a person is currently experiencing. On the UPDRS, the categories that are used to define the person’s level of speech ability are not specific enough to capture any information about how patients actually manage real conversations. The only ways of classing speech ability on the UPDRS are limited to the following descriptions and levels: “0=normal; 1=slight loss of expression; 2=monotone, slurred but understandable, moderately impaired; 3=marked impairment, difficult to understand; 4=unintelligible” (UPDRS Organization). In fact, to date, there is still no widely accepted and comprehensive method for assessing communicative functions of speech in PD.

The results of the biomedical line of research have contributed basic recommendations for speech therapy, such as training in clear speech (Goberman & Elmer, 2005) or improving

vocal loudness (LSVT), yet no approaches to therapy from the biomedical approach have led to formulations of therapy that train the functional skills of a person with PD in conjunction with their family members or other communication partners.

In efforts to take into account the psychological and social aspects of speaking, some researchers (Whitworth et al., 1999) have conducted studies on patients' perceptions of their intelligibility and used questionnaires to discover the impaired speakers' feelings about their difficulties interacting through conversation. Although researchers recorded samples of live conversations in the homes of people with PD, the segments subjected to analysis were only 10 minutes in duration. The authors acknowledge that this small data collection led to difficulties in drawing any firm or significant conclusions, as problems the subjects claimed they experienced did not manifest in the short samples of conversation data.

Whitworth et al. (1999) were able to identify strategies that conversation partners developed to manage conversations with the person with PD. The authors describe facilitatory coping strategies as "problems solving" measures and then create more detailed categories of facilitation, such as "provision of target output," but again, like other research reviewed in this chapter, they do not look at the details of the interaction: that is, they do not examine when and how the strategies are deployed in actual conversations. Furthermore, Whitworth et al. (1999) are exclusively interested in the role of the conversation partner rather than looking at how the interlocutors work in concert to create meaning.

In a similar approach to understanding speech interaction in PD, Kegl and Poizner (1998) also analyze the behavior of the person who is not neurologically impaired. They claim that in this way they can best understand the communication of the person with PD. They also do not

look at how the actions of the speakers mutually constitute each other in an ongoing fashion (i.e. they do not consider actions to be co-constructed).

Summary of Literature on Alzheimer's

Research that examines live speech in Alzheimer's disease (Hamilton, 1991, 1999; Sabat, 1999) provides useful models for the study of repair, clarification requests, accommodation on the part of the conversation partner, and taking the role of the other. These areas of study are very relevant to the study of speech in Alzheimer's as the disease is characterized by lapses in memory that may cause non sequitur speech, thus calling for repair and accommodation on the part of the interlocutor. Again in this research, there is an emphasis on the role of the interlocutor rather than on the actions the partners perform together.

Summary of Literature on Aphasia

In studies on interaction with people with aphasia, researchers have examined repair, word searches, functional laughter, and creative word orders. Throughout this literature, authors use their conclusions to recommend that speech therapy be done in groups or family settings. The most extensive work on interaction with stroke-induced aphasia comes from Charles Goodwin, who followed his own father's interactions over eight years. Through the years, Goodwin has made significant contributions to theories on gaze, gesture, and methods for applied CA. In fact, he is often credited as being the founder of the video branch of CA work (Have, 1999). Regardless of the particular interactional mechanism he is focusing on in any given study, Goodwin generally analyzes how the actions of interlocutors function in concert. His work also provides the same general implication throughout that language competence can only be measured in terms of communicative functionality within a socially and semiotically

meaningful environment. Additionally, Goodwin often concludes with the same recommendation for group therapies for families learning to manage stroke.

Until 2004, Goodwin used the third person to label the interactants in his publications. For example, his father is always called “Chil” and when Goodwin himself is an interactant, he calls himself, “Chuck.” Even when Goodwin begins papers with the announcement that Chil is his father, he still refers to himself as “Chuck” and his father as “Chil.” While I cannot claim to know why Goodwin chose this approach, I may be able to safely assume that it is because he is steeped in the methods of CA, which traditionally encourage analysts not to assume *a priori* that social categories are relevant to an interaction. Thus, in Goodwin’s case, he may not be using the categories of “father” and “son” because the types of interactions he is looking at can be explained and understood without reference to these familial categories. Perhaps his third person approach is an attempt to make his analysis appear somewhat more objective⁴.

Yet it is my contention that not claiming these family relationships outright limits Goodwin’s analyses. As an analyst outside of the interaction and also a son in the interaction, Goodwin has a privileged epistemic stance: he knows things that other analysts (and also his readers) unaware of the relationship and shared lifetime history would not know. This knowledge becomes problematic only because he has not positioned himself as one who has the “insider knowledge” that he nonetheless draws on in his analysis. The clearest example of this problem occurs in Goodwin’s analysis of “Chuck” and “Chil’s discussion of going for a drive “along the river” or “up Bear Mountain” (Goodwin, 2006). From the non-privileged stance of a third person analyst, the only thing Goodwin should be able to claim in his analysis is that “Chuck” eventually provided the solution Chil was looking for in stating “Bear Mountain.” From the

⁴ Admittedly, this choice may also be something as simple as journal editors’ preferences. The consistency with which Goodwin uses this presentation, however, leads me to believe otherwise.

objective stance of a third person analyst and without stating how he knows what he knows, he should not be able to go further and conjecture (as he does) that he knows *why* Chuck was able to predict the correct solution. Goodwin claims that the success of this communicative event relied on the two interlocutors inhabiting “what Clark refers to as common ground” (Goodwin, 2006, p. 18). Goodwin explains that the two interlocutors inhabit “together an extended, meaningful geographic and social space with features and directions that they recognize in common” (p. 18).

Indeed, Goodwin’s discussion of “common ground” and shared mental states is the most interesting point to make about this interaction. Simply stating that Chuck got the right answer is neither groundbreaking, nor interesting news. In my view, however, Goodwin’s readers simply have to take him at his word that this interaction illustrates common ground, as he has not justified how he knows the two speakers share anything more than this short interaction together. Because Goodwin has not specified the lifelong father-son relationship between the interlocutors in his excerpt, the reader is left with a limited understanding of how he can claim anything at all about the physical or mental spaces they inhabit together. In my opinion not positioning himself in his research weakens his arguments by asking readers to take as read certain claims in his analysis. By not claiming his epistemic stance, Goodwin may appear to some as a less credible analyst.

In studies on PD, Alzheimer’s, and stroke-induced aphasia, researchers are turning to methods of data collection that enable them to view people’s functional communication abilities. Researchers adopting this approach are making tremendous inroads into discovering how these different diseases affect the daily lives of people with such diseases and their families. In the next section, however, I point out areas where research on PD can be furthered.

Addressing the Gaps in the Literature Through this Dissertation

I have provided a comprehensive review of Goodwin's body of work in order to establish how the direction I take in my research on interactions with people with PD is an extension of his work on aphasia. Basing my research on his detailed analyses of meaning making with someone with such an impaired lexical repertoire, I investigate how the same processes Goodwin has identified may be the same as or different from those involved in speaking to a man with PD. While my work is modeled on Goodwin's, there are also ways in which my research is different, providing unique contributions to the literature on conversational interaction with people with neurogenic speech disorders.

First, it should be noted that stroke and Parkinson's engender different pathologies. In stroke, patients may entirely lose their ability to use words to communicate or they may retain only a handful of words, as in Chil's case. Over the first few months of therapy, however, patients may begin to recover some of their linguistic repertoire and skills. Also, depending on what area of the brain experiences the ischemic attack that is a stroke, patients may retain their memory of words while losing their ability to order them in syntactically appropriate ways.

In PD, on the other hand, patients' speech abilities gradually erode over many years. While people with PD may experience some word finding difficulties, they generally do not entirely lose their ability to recall or use words to convey meaning. Nor do people with PD lose the ability to string words together in order to create syntactically ordered sentences. People with PD do, however, lose the ability to make their streams of sound distinguishable, thus making it increasingly difficult for their interlocutors to parse out words or to use their intact syntax as a way of making sense of their utterances. In simple terms, people with PD can use words and syntax, but the people they are talking to cannot always figure out what the words are.

My work also differs from Goodwin's in another fundamental way: throughout my research, I explicitly discuss the familial relationships between interactants and refer to myself in the first person in my analysis. I include short narratives that serve as additional background information on the people who are involved in the data. I do this because this approach works to enhance readers' understanding of my analysis, given that they have insight into my epistemic stance: the reader is invited to know what I know and how I know it.

Bringing Goodwin's work on stroke to research on PD is one of the primary ways in which I hope to contribute to literature on PD. To date, the only work that has been done to analyze conversational interaction with people with PD has produced only 10 minutes of data per subject, a sparse amount that the researchers admit was inadequate. I instead draw on a database of approximately twenty-three hours of conversations between one person with PD and his multiple interlocutors. This data set allows me to better determine what conversational strategies are anomalies versus patterns and to perhaps draw conclusions that are borne out more noticeably throughout the data.

My research also aims to fill in the gap left by previous work on communication strategies developed by those who speak with people with PD. Rather than looking exclusively at how conversation partners develop alternative strategies. I examine the actions of all the interlocutors involved, viewing the creation of meaning as a process of co-construction. Instead of cataloging how non-impaired partners accommodate or adapt, I analyze the turn-by-turn details of how the interlocutors work in concert with one another to come to understandings.

Finally, through this dissertation, I hope to contribute to a small but growing collection of literature that stresses the need to assess and provide therapy for people with PD-related speech disorders as they function conversationally on a day-to-day basis. In time, I hope that work such

as this will begin to trickle into communities outside of academia, encouraging a view of those considered to be disabled as “differently-abled” instead. I emphasize the idea that although one avenue of meaning making may be impaired, people with PD and their partners find alternative and perhaps equally meaningful ways of interacting. This view frames people with PD as having multiple additional competences rather than being incompetent.

CHAPTER 3: PERSONAL EXPERIENCES THAT FRAME THE RESEARCH

In a letter to his friend Jean Floud, philosopher Isaiah Berlin (1968) wrote, “All central beliefs on human matters spring from a personal predicament.” This quote served as a guiding principle for the Athens Discourse Inquiry Group (ADIG), established in Athens, Georgia by Dr. Betsy Rymes in 2003. As participants in this group, we encouraged each other to bring readings to the table that addressed our particular areas of interest within discourse studies. During the time that I participated in these meetings (2004-2006) and from working under the supervision of Dr. Rymes, I became increasingly aware that my thinking about language and Linguistics was shaped by the unique communicative interactions I experienced in my family throughout my life. As I continued through my doctoral program, remembering Berlin’s quote led me to believe that academic research is most compelling when a researcher has a vested interest in answering personally troubling questions.

Purpose and Organization of this Chapter

The primary purpose of this chapter is to illustrate the personal predicaments that have motivated and shaped the present study. Here, I outline the structure of this chapter while explaining in more detail the specific purposes of each section. In the next section entitled, *Growing up with Harold*, I include a narrative and background information on my Uncle Harold, who was born with severe mental and physical disabilities. As my mother grew up with Harold as her brother, she naturally negotiated changing roles over the years, moving from being a sister, friend, and interpreter of his language into the role of a caregiver. My own experiences with Harold followed a similar trajectory. When I was younger, I viewed Harold as a playmate. I

also helped interpret his language so he could communicate with the world outside our family. As I grew capable of taking on greater responsibilities, I also became an additional caregiver to Harold over several weeks a year. There are many ways in which these experiences inform the present study.

The first function of this section on Harold is to demonstrate how my mother and I were very close to a family member who we considered to be a competent social actor despite his severe limitations. I include examples of Harold's lexicon in order to underscore that Harold was not just competent, but actually very creative. I believe that our background with Harold allows both my mother and me to take very seriously issues of purported incompetence or disability. This lifelong experience of encouraging others to see Harold as competent is at the root of my stance on Linguistic theory, which will be explained fully in Chapter 4. The narrative and transcripts on Harold lays the foundation for why I view language and Linguistics as I do.

Second, this section serves to illustrate how my family is accustomed to being an essential part of a member's language ability. The transcripts demonstrate how Harold was able to communicate successfully because his family developed alternative systems of communication and worked with him to understand the innovative language he created. We have transferred these strategies from our interactions with Harold to interactions with Dad. Knowing that we have been using many of the same communication techniques over many decades may help readers gain insight into the data analysis performed for this study.

Finally, the transcripts of our interactions with Harold are a way of introducing the strategies that will be explored in greater detail in the findings chapters in this dissertation. We all use gesture, gaze, intonational changes, multiple repeats and negotiations of meaning in combination with our previous life experiences in order to communicate with Harold. Viewing

these transcripts and cursory analysis of interactions with Harold allows readers to see that the strategies a family develops to communicate with a member who has speech disabilities can actually be transferred to other situations. This provides support for the argument I maintain throughout the dissertation that a community of speakers can evolve skills that can be shared with other families or communities of speakers who may be coping with similar communication hindrances.

The section entitled, *Early Family History* is designed to introduce readers to my parents who are two primary research subjects in this project. This short narrative presents my father as a jokester and a lively character. These traits still factor heavily in our present interactions and in the findings of this study.

I include the next section entitled, *Memories of Dad before Parkinson's* in order to set up the contrast between Dad's daily routine and physical abilities before the disease and his current physical limitations which I then explain in the section entitled, *The Current State of Affairs*. As Dad's physical changes factor strongly in the types of alternative communication our family uses, and because Dad was such a physically active person before the symptoms of the disease took hold, I feel it is necessary to describe how PD affects his daily activities. To fill in the chronological gaps between these two sections and to describe the process through which Dad has come to terms with PD, I then include a section entitled, *Twenty-Three Years Along the Lines of Parkinson's Travels*.

Finally, I include my *Subjectivities Statement* to demonstrate how I am integrating these personal experiences and this current study. In this section I position myself within my research and demonstrate how my lifetime of experiences with alternative communication necessitates my adoption of the concept of co-construction of meaning.

In this chapter, I invite readers to share my insider's perspective on the dynamics and history of my family. While outwardly every family appears to be churning through the same motions of work, school, and play, I believe that no outsider's point-of-view can do justice to representations of the distinctive ways in which one particular family grapples with the vicissitudes of life. The colorful fabric that is my family displays a unique weave of personal stories. Only an insider who has been socialized through this weaving process can provide insight into this process. I now turn to telling my family's story with the hope that you can see the threads that are interwoven to form the patterns of how we now exist in this world.

Growing up with Harold

My mother's childhood on an Indiana farm at the tail end of the Great Depression with second generation German immigrant parents still serves as a framework through which she views and interacts with the world. Picture the house, values, and lifestyle of the famous TV family, *The Waltons*, minus their anachronistic postmodern interpretation of farm life where everyone's personal hardships and motivations are taken into account before the family passes judgment. My grandparents could not afford to tolerate such iniquities as laziness or frivolity. My mother and her sister used to revel in the indulgence of sharing a soda every once in awhile or in going to see a movie once a year. My grandfather loathed the very idea of going to a drive-in movie: why pay 25 cents for his ticket knowing that he would immediately surrender to sleep due to utter exhaustion from day after day of hard physical labor on the farm?

What this family needed was a strong son to fill the boots of a dedicated farmhand and help ease some of the labor burden from my grandfather's shoulders. What they got instead were two daughters and a son around whose neck the umbilical cord was wrapped far too long during delivery, resulting in irrevocable brain damage. Harold was always "grandma's boy," but he

actually increased the family's workload significantly. My grandparents were told that he was so severely mentally disabled (the Doctors' language of the time actually labeled him as so "retarded") that he would never learn to walk or talk. When the time came for a child to take his first steps, Harold didn't. It was then that Grandma held him under his arms or wrapped a dishtowel around his chest to hold him upright while my Aunt Marilyn, the oldest, manually marched his legs up and down until his muscles gained strength and learned to do it for themselves.

Doctors generally estimated that Harold's mental age was frozen at about the age of a two-year-old. Yet, he could perform amazingly cunning manipulations. He was known for stealing grandma's magazines, ripping the pages out, and then folding them up so he could carry them around in his pocket for days. He put them under his pillow at night. If any of us ever tried to remove them, we would pay dearly with his temper tantrum in the morning. Because he got in trouble so many times for taking the magazines, Harold devised a plan to wait until my grandmother had fallen asleep for her afternoon nap on the sofa, newspaper in hand and mouth gaping open. I once watched him creep over to her to take the *Parade* entertainment magazine out of the middle of the paper without stirring her. He then took out all the insides and placed the outside cover back in exactly the same spot inside her newspaper. This at least served to stave off Grandma's noticing long enough for him to hide his prized booty.

To say that Harold never learned to talk would be to discount the unbelievable creativity and intelligence that he displayed when creating and using his own language to fulfill all his needs or desires. Yet, his mental and physical handicaps he was born with were not the only obstacles he had to negotiate in order to express himself. During Harold's teenage years, he used to grit and grind his teeth so badly during the night that his pillow would be completely soaked in

blood the next morning. Thanks to my grandparents' depression era frugality, I have actually seen these pillows that they could never throw away for fear that they would have to then waste money on replacements. The solution of the rural doctors at the time was to surgically remove each and every tooth in Harold's head, leaving him with only gums and lips for eating or communication. The ultimate effect was that Harold could say only a few words that sounded like English, such as "bye-bye," "momma," and "meow-meow" (for cat). Despite his limited ability to form words, Harold still had a communication repertoire that he used to interact with others in his own unique way.

Without explicit training from his family, Harold observed the world around him and came up with his own set of onomatopoeic sound clusters, which when used in conjunction with particular gestures, facial expressions, and vocal tones could convey multiple meanings. The time and space context in which he deployed these combinations also contributed to his construction of meaning. For the most part, Harold was excellent at understanding conversations around him as long as they concerned things that interested him. In fact, my mother recalls how my grandparents had to resort to speaking in broken German at times to prevent him from understanding their plans.

To illustrate how Harold thwarted his physical and mental limitations to language production, I include below some examples of his basic vocabulary. For a more complete list of his lexicon, see Appendix A. Note how very few of Harold's recognizable units of meaning would actually be considered to be "words."

Examples from Harold's Lexicon

1. Cat: "meow, meow"
2. Tractor: "pimm pimm pimm pimm" (*indicative of the puttering noise made by Grandpa's John Deere tractor*)
3. School: "mmmm.mmmm.mmmm." (*rubbing his index finger from one hand rapidly back and forth in the palm of the other, imitating writing*)
4. Teacher: "mmmm.mmmm.mmmm." (*tapping his index finger lightly against his eyelid, as though indicating 'someone he is supposed to watch'*)
5. Church: "dum dum" (*making his hand into a pointing gesture then moving his hand and arm up and down to indicate ringing of the bells*)
6. A visitor staying overnight: (*A snorting sound indicating snoring or sleeping made while patting the arm of whomever is staying*)
7. My name/my mother's name: "ooolll" (*sticking his tongue far out, indicating vomiting or crying*)
8. Mom, Dad, anybody whose attention he needed: "mama"
9. Drink/drinking: "dud-dee" (*while making the hand motion of having something to drink*)
10. You should/you are go/going home on a plane: "zzzwwwweeeuh" (*quickly drawing an arc over his head with his hand, as though signifying flying overhead*)
11. Get out of my way: "beep beep," (*making the motion of shooing others away*)

12. Universal sound cluster employed with different tones of voice, depending on the context: “nyuh nyuh nyuhnyunyu”

While most of Harold’s units of meaning were standard in that they were used to indicate the same ideas or objects repeatedly, much of what he said was only interpretable based on where his utterance or gesture fell within the context of others’ ongoing activities or conversations. For example, if his mother (my grandmother) had gone to a doctor’s appointment in the morning with my mother while I stayed at home with him, if he would nod toward the door and ask, “nyuh nyuh nyuhnyunyu?” I could immediately respond to with, “Don’t worry, they’ll be home soon.” I knew that Harold was terrified of doctors and hospitals and very much disliked the idea of anyone in the family having to see a doctor.

Similarly, “bye bye bye bye” could have its own range of meanings that we could understand based on where he said it in relation to the ongoing conversations and the tone of voice he used when speaking. For example, if there had been recent talk about going to town to run errands and have lunch (activities Harold loved), he would ask, “bye bye bye bye?” and we would know to respond with, “Yes, Harold we’re going to town,” although admittedly we sometimes delivered the same lines with increasingly annoyed tones in our own voices each time we answered the same question dozens of times within the couple of hours before leaving. If instead my brother had just taken candy from a bowl Harold had decided was off limits to Andrew and Harold yelled, “bye bye bye bye!!,” Andrew would know that he’d just been told off, or more specifically, to “go home” (“to go bye-bye”).

Clearly, even though Harold had such incredible limitations to his ability to speak, he was able to convey complex thoughts. His gestures and sound combinations were not merely iconic representations or direct references to objects, but were instead the components of a functional

language. As we negotiated the outside world with Harold, our family members served as his interpreters. Only the closest family friends or people who worked over many years with Harold at his Day Care centers knew how to interpret most of his utterances. As we see in the transcripts below, we all had rich interactions with Harold that call into question strict traditional definitions of language competence, perceptions that meaning in language is opaque and fixed, and classifications of the mental abilities of the disabled.



Figure 1. Harold points over his shoulder

Harold and His Movie

A= my brother, Andrew; H= Harold; M= Mom

1 A: (*pointing to Harold's video*)

2 H: Eh..mmmm

- 3 *(rubbing index finger in palm = 'school')*
- 4 A: *(nods head in understanding)*
- 5 M: can we watch it first at home?
- 6 H: *(doing sign for school again)*
- 7 A: you wanna watch it at home?
- 8 H: *(doing sign for "over there/back there" + school = "I want to take this back to my*
- 10 *group home and watch it there")*
- 11 M: you wanna take it back with you?

This interaction between Harold and my brother takes place right after opening Christmas presents. My brother initiates the conversation with a simple gesture of pointing to a video Harold has just received as a gift. Harold interprets my brother's gesture as meaningful and responds with a declarative statement by rubbing his index finger from one hand in the palm of his other hand. As my entire family is fluent in Harold's language (See Appendix A to note that his vocabulary is limited to only a few topics that interest him most), my brother Andrew simply nods his head in response (line 4). My mother also immediately understands Harold's meaningful gesture and then enters into the conversation herself by asking if we can watch the video at home first (line 5). In defiance of her suggestion, Harold repeats the sign for school more vigorously (line 6). Taking up Mom's agenda, Andrew rephrases her original question into a more pointed query as he asks if Harold wants to watch the video at home (line 7). Specifying his desire to watch his video only at school, Harold adds in the extra signs that denote "over there" or in this case it might be more accurate to interpret the signs as "not here" (line 10).

This entire conversation relies on gestures and unique sound combinations that are understood only by Harold's family members. Although Harold was considered by the outside

world to be an insignificant conversationalist, he was clearly capable not just of having meaningful conversations but also of being a powerful social actor: here Harold is clearly determined to have us accept his point of view. In the next transcribed interaction, on the other hand, we will see how members of the family use standard conversational strategies to elicit utterances from Harold that fit our agenda rather than his.



Figure 2. Harold makes his hand gesture to indicate “gloves”

As long as my grandfather was alive, my grandparents’ home remained a working farm. Harold loved to help out with the farm chores, but my mother remembers that if grandpa were ever doing a chore Harold did not want to participate in, he would pretend grandma needed him in the kitchen and then go back inside to be with grandma. When Harold was outside working with my grandfather, he always wore work gloves.

After grandpa passed, there were no more farm activities, but Harold retained an obsessive attachment to his work gloves. Along with his pocketful of papers, a handkerchief, a pencil, and a comb, Harold always carried with him a pair of work gloves sturdy enough to protect his hands from the harsh outdoor work. But the gloves never found their way to the barbed wire, hay, and gasoline they were made to contend with. Instead, they stayed on the sofa tucked under Harold's thigh. They became the object of protection themselves, his most prized possession. At times, he would pull them out and wear them, wringing his hands and pondering their texture in meditative repetition. Each year at Christmas, the family had a tradition of giving Harold a new pair of gloves. As the gloves were always his most cherished gift, we learned to give them to him last. We knew that if we didn't, he would have no interest in anything else he opened.

The transcript that follows is from Christmas 1996. We were nearing the end of our morning of gift giving and we had taken a break to ask Harold what he was still waiting to receive. Over the years of going through this same routine with Harold at Christmas, we had cultivated his expectation that Santa would always bring him gloves. It is with unwavering certainty then that upon our inquiry he confidently declares that Santa has brought him gloves:

Harold and His Gloves

C= my cousin; H= Harold, also called "Butchie" at times; A= Amy

- 1 C: Butchie, what? [what are you wanting?]
- 2 A: [what are you looking for?]
- 3 H: Mmmmm
- 4 (making his sign for 'gloves')
- 5 A: Gloves?

6 H: Brrrr

7 *(his sound for “cold”)*

8 A: Who brought you gloves?

9 H: Brrr

10 *(tossing his head up and back: “cold” + “someone came here” = “Santa”)*

11 A: Santa brought you gloves?

12 H: Mmmhmm.

(nodding his head in approval)

On the video from which this transcript is excerpted, Harold is visibly agitated. There are no gifts left to open under the tree, because we often hid the package of gloves somewhere else to avoid giving them to him prematurely. Assuming he is bothered by the gift-giving session coming to an end without the appearance of new gloves, my cousin and I ask him what it is that he is still looking for.

In line 3, Harold makes the continuous sound “mmmm”, almost like a hum that carries a declarative tone, in conjunction with his sign for gloves (moving his interlaced fingers back and forth as though pushing the web of cloth in between the fingers on his imaginary gloves deep down into the inter-digital space to secure the gloves tightly on his hands). Being well acquainted with this particular sign and sound combination, I offer, “gloves?” in line 5. Rather than having to repeat his gesture for gloves, Harold is able to go on to express a new idea about the gloves, saying “brrrr” in line 6. I know this means “cold” in Harold’s language, an indication that he needs the gloves to protect him from the cold weather. Understanding his meaning, I do not need to question him for clarification, but instead move on to a new question. In line 8, I offer, “Who brought you gloves?” which builds on previously established shared meanings and builds a

bridge to our expanding conversation. When Harold answers in line 9, he makes his sign for “cold” and “someone came here,” which I think means, “Santa.” To clarify and perhaps just to continue the conversation, I ask, “Santa brought you gloves?”

Throughout the entire exchange, it is as though I am translating Harold’s gestural signs and utterances into English in order to make this into a public conversation. It is as though in lines 5 and 11 I am doing the process of sedimenting correlations between signs and words for the community of speakers present (and likely also for the video camera). This conversation takes the form of a negotiation rather than a simple question-answer sequence where declarative meaning is directly conveyed from a speaker to a listener.

The first transcript, *Harold and his Movie*, starts out with Andrew initiating a genuine conversation by pointing to Harold’s video. In the conversation that ensues, despite the efforts of Andrew and Mom to get Harold to accommodate to their agenda, Harold repeatedly insists that they accept his plans. The negotiation takes the form of multiple repeats on Harold’s behalf so that he can continually emphasize his meaning.

This second transcript entitled, *Harold and his Gloves*, displays a different type of interaction. Here, my cousin and I have initiated the conversation about the gloves as a way of getting Harold to run through our standard routine of talking about his expectations for receiving gloves. We have a pre-set agenda and are implementing a standard choreography of linguistic actions in order to elicit the conversation we want to have with Harold. The questions we ask Harold here actually limit and somewhat determine the answers he will give. We ask him, “What are you wanting?” (line 1), “what are you looking for?” (line 2) and “who brought you gloves?” (line 8). Through these questions, my cousin and I create co-create meaning with Harold, developing a conversation that may not have happened otherwise.

These experiences communicating with Harold shape the ways in which Mom, Andrew, and I now interact with my father. We are accustomed to using alternative strategies to communicate when a family member's ability to create distinct words is impaired. In this dissertation we will see that my family relies on gesture, gaze, a physical environment that has sedimented meanings, scaffolding practices, and a lifetime of knowledge about each other's communication norms in order to co-construct meaning. The strategies we employed for years with Harold are also instrumental in our meaning making with Dad.

Early Family History

By July of 1970, a young woman from a farm in Indiana had typed and “yes sir”-ed her way to a corner office on Rockefeller Plaza in downtown New York City. Growing up in the country had given her an intense curiosity about city life, which led her to explore and claim familiarity with many of the attractions in NYC. At work, she was often called upon to entertain out of town guests, as she loved to tour them around and let them see the city through her eyes. One weekend, her friends invited her to a dinner party with the expectation that she would meet and then set up a time to escort two school headmasters visiting from the Bahamas around NYC. A balding tire salesman from England who had recently relocated to NYC was also invited to the party.

Feeling the festive mood of the evening, this man brewed up his unique brand of British mischief. He pretended to drop his pen at the young secretary's feet. While kneeling on the ground, he reached over to the woman's open-toed shoes and pulled her pantyhose straight off her toes through the opening, and then let them snap back into form. Satisfied with the anticipated shriek of surprise he received from the young woman, the man rose to his feet and said, “Sorry to bother you. I've been doing a survey to find out how many women here at the

party tonight are wearing nylons. You see, I've just bought stock in a company that makes nylons and am doing market research to see if I've made a wise investment."

The woman had never given out her number to a stranger before, but this one had swept her off her feet – or almost anyway, at least in the literal sense. By Christmas of 1971, they were engaged and three months thereafter, they were married. They brought a boy into the world in 1974 and a girl in 1976. For the first nine years of their marriage my parents were apart quite a bit as my father traveled the Northeast selling tires to distributors while my mother worked from home and raised my brother and me. Money was tight during that first decade of Heaton family life and Dad skipped breakfast and lunch everyday to save up his stipend.



Figure 3. Dad imitates his Navy sergeant to amuse his friends

Memories of Dad Before Parkinson's

As a British transplant to Long Island, NY, my father found plenty of the activities he enjoyed in the motherland still available to him. He played in the local cricket league and the North Shore Symphony, sailed in the Long Island Sound, and coached his children's soccer teams.

I don't have many memories of my father ever sitting down. He was either mowing the lawn, working in the garden, practicing his violin, or creating a new scene on his model railway in the basement. My mother recently reminded me of the "Daddy Fitchet" table by the door to the garage. Anytime my brother or I would mangle a toy, my mother told us to put it on this table so daddy could fix it when he got home. As soon as he walked in the door, my brother would run over and show him the victim and demand, "Daddy, Fitchet." Even though my father spent most of his childhood in a boarding school and had no model for hands-on parenting in his past, he was involved in our every activity and was always there to help fix our problems.

At any point during his daily activities, my father was known to whistle whatever the most complicated part of a particular symphony might be, never missing the subtle pitch changes or failing to match the speed and precision of the second violins' thirty-second notes. Or, my father could be suddenly possessed by his own interpretations of the Ministry of Silly walks, the Gumbys, or sketches from his all-time favorite show, Fawlty Towers. In nearly any crowd, my father could find his place as the life of the party.

The Current State of Affairs

I have come almost 23 years along the lines of Parkinson's travels. The neurology doctor thinks I might have Alzheimer's too and life is a pretty poor quality. I enjoy food and sleeping and don't tolerate friends too easily. It's true that I have

declined to current levels where I cannot walk and my speech has almost dried up.

Because I cannot be understood, I don't recommend Parkinson's Disease to anyone (Peter Heaton, in a statement prepared for his medical intake interview at The Daoist Traditions Chinese Medicine School)

As we see in the quote above, despite the grim outlook of Dad's present life, he still retains his sense of humor, stating that he "[doesn't] recommend Parkinson's Disease to anyone." Dad still has the same intensity of personality, comedic spirit, and burning drive for perfection yet it is all trapped inside the body of a seventy-two-year-old man hunched over and leaning to the right in his wheelchair. While we may catch my father crawling slowly across the living room to put a CD in the player, he can no longer use his legs to walk. He reports that he has no feeling in most of his fingers, a sensation which we can witness through his many failed attempts to grasp anything from a water bottle to a spoon or even a piece of paper. His hands are mangled from multiple falls after which he never brought a major injury to anyone's attention so that he could receive proper care. In fact, I remember a vacation weekend to the mountains about five years ago when dad caught himself with his hands as he fell. He very obviously broke his finger, but instead of letting us ruin our weekend taking him to the hospital to have his finger set properly, he sat at the dining room table and set it himself. The current condition of his finger is a daily reminder that this was a terrible decision.

The incapacities resulting from his limited sense of touch are further compounded by his double vision: he often appears to be reaching for the illusory piece of toast rather than the real one. Throughout the day, my father finds it difficult to keep his eyes open for longer than just the time it takes to eat a meal, which is now increasingly often fed *to* him. He has almost completely lost control of his speech articulators, including his lips, tongue, and vocal tract. His speech has

been reduced to a mostly unintelligible stream of sounds, only barely decipherable by his closest family members after long and complicated negotiations. The concatenation of all these limitations makes my father someone who needs a great deal of assistance to dress, bathe, use the restroom, eat, take his medications, turn on the TV, and so forth. Parkinson's Disease has so severely crippled my father that he is able to enjoy neither any of his more extraordinary activities nor even his normal human abilities to perform everyday tasks for himself.

Twenty-Three Years Along the Lines of Parkinson's Travels

When my father was first diagnosed with Parkinson's Disease, he was only 48 years old and inquiring into what seemed to be a lazy right arm and leg. He believes that he had the disease for at least one year before the official diagnosis. When my parents decided to tell my older brother and me, we were probably about 10 and 12 years old. At this time, the medical community did not seem to know quite what to do with early onset Parkinson's patients. While the particular group of symptoms known as Parkinson's Disease (PD) had been named such for some time, they were mostly presenting in older people. We were told that within two years, my father would be in a wheelchair and within five he would probably be dead. Little did I know then that my father's strong personality, sense of humor, and dedicated spouse would allow him to outperform all expectations.

In the 23 years since my father was diagnosed with PD, his articulatory speech abilities have gradually eroded. This difficulty has been particularly salient during the last ten years. Speech therapy has only been prescribed for him twice. The therapists used the only treatment protocol that has proved itself at all successful in helping PD patients to communicate more effectively. While this Lee Silverman Voice Treatment (LSVT) does produce controlled volume improvement, no other aspects of language production or context-embedded abilities to function

through language are addressed. In both cases the treatments were ended due to the speech language pathologists' assessments that my father's speech could not improve. Our family was told that my father's health insurance provider would not continue to pay for therapy for someone who could not show marked improvement from session to session. This is a tall order for someone working with a degenerative disease. My family has come to understand that focusing on my father's deficient language skills in speech therapy may never amount to anything more than an exercise in treading water, where he is constantly working, yet able to do nothing more than barely keep his head above water. Despite the lack of speech therapy services provided for my father, my family is still able to use a mix of compensatory and alternative strategies in order to communicate with him. Noticing how difficult it is for people outside our family to communicate with my father, I became motivated to explore the unique ways that we do manage to make meaning with him.

Subjectivities Statement

Integrating life experiences with academic work has always been my most effective and meaningful learning strategy. In my Linguistics program, I have been drawn to research paradigms that can best explain language phenomena I have observed throughout my life. In this dissertation, I merge my personal history and theoretical stance on linguistic inquiry in such a way that they may mutually inform one another.

During my entire life, I have been surrounded by family members who use alternative means to communicate. As we have seen, my uncle Harold invented an entire language of his own, often repeating the same phonological stream of sound in conjunction with infinite combinations of tone and gesture to meet his communicative needs. Another uncle was the victim of brain injuries and strokes who spoke in long, drawn-out syllables and repetitious

formulaic language. As he was also nearly deaf, my family and his caregivers spoke to him through exaggerated mouth and lip gestures or by writing on a portable white board. Finally, my own father's speech has been profoundly affected by his Parkinson's disease. He has such difficulty controlling his volume, facial expressions, and speech articulators that successfully conveying any message requires that his interlocutors negotiate his meaning using numerous interacting semiotic layers.

All the family experiences described in this chapter have served as a filter through which I assimilated new information on Linguistic theory during my graduate program. Also, these experiences affected how I designed my research for this dissertation. In order to better understand my subjectivities and motivations for this study, I now turn to a description of my experience as a research assistant. As we will see, the interactions I had with my research participants has had a profound impact on how I have chosen to develop my own study.

As an assistant to an academic research project, I had the opportunity to work with multiple stroke patients. As part of my duties, I administered the Boston Diagnostic Aphasia Exam (BDAE) to hospital patients who had very recently suffered a stroke. The section of the BDAE that is entitled, *Conversational and Expository Speech* consists of a few short questions such as "How are you today?," "When are you going to be leaving here?," "What is your full name?," and "What is your address?" (Goodglass, Kaplan, & Barresi, 2001, p. 2). Next, the examiner is to elicit conversation by asking "What kind of work were you doing before you became ill?" and "Tell me what happened to bring you here." Here, the examiner is to "encourage at least three minutes of conversation, if possible" (p. 2). Finally, the stroke patient is given a picture of events occurring in a common kitchen scene and is asked to describe everything "going on" in the picture (p.3).

On the very next page, the examiner is to rate the patient's "speech output" on the exercises using categories such as "articulatory agility," "phrase length," "melodic line," and "word finding relative to fluency." (Goodglass et al., 2001, p. 2). In administering this test to stroke patients, it has been my experience that it is very difficult to determine anything accurate or useful about the person's capability to produce speech from the types of questions asked in the limited time provided.

In only one case (out of my admittedly limited experience testing about a dozen or so people) did the question "Tell me what happened to bring you here" elicit a long and detailed response. This patient was able to explain to me that he had already been in a wheel chair before his stroke because of a car wreck. He was sitting in his wheelchair in the woods near his house when he had his stroke. He then fell out of the chair and landed in a cluster of fire ants, but could not move away from them. That night, a terrible ice storm came and as the roads were so treacherous, no one in his family came to check on him, leaving him on the ground in freezing temperatures for over 24 hours.

Although I do happen to believe the man's story, I don't take the discussion of the veracity of his claims to be relevant here. What I do find intriguing, however, is that his vocabulary and syntax were so extremely limited that he could only say a handful of single words such as "chair," "car," "yes," and "no". He was also able to count on his fingers. Despite these limitations, he was able to tell me about the fire ants by picking up one of my exam books and flipping through to the picture of an ant. He made wind noises and gestures to recall the storm of the previous week. He could make body movements in conjunction with noises to indicate to me that he fell. As he provided signs through multiple semiotic channels (e.g. sounds, body orientations, hand movements, smiles, etc.), I provided the bulk of the more complex

linguistic material, waiting for him to either ratify or reject my suggestions before moving on. Throughout this part of the examination, I recalled my training that strongly emphasized that the examiner is not to give anything more than one word prompts. Despite this requirement, I opted to help this man tell a story that was very important to him and figured I would deal with the research complications later. This very complex conversation probably took between 15 and 20 minutes.

Administration of the BDAE is not generally meant to elicit such elaborate discourses from people with this man's level of impairment. In fact, understanding such a detailed story could not be done with an examiner who chose not to participate as a co-author. Yet, because I have had so many family members who have been in similarly frustrating communication predicaments, I found it almost impossible to maintain my strict role as examiner rather than helping this person have a genuine and meaningful interaction with another human being.

Although this man's linguistic sound inventory was severely reduced, he was capable of both language comprehension and production at a level that could not be appropriately measured through the BDAE. This man's language capacity was not located in his own brain, but in the semiotically rich space between our minds where facial expressions, body comportment, material objects in the room, hand gestures, and vocal sounds were synergistically layered to produce meaning. It is in this sense that communication is a "*public* sign system" (Goodwin, 2004).

Unfortunately, those with language disabilities are still examined in clinical settings based on the notion that an ability to perform language tasks is the job of a lone individual. I found that clinical tests are generally context-removed and consist of tasks that are of little personal interest to the patient. This language exam only tested for a very limited view of

language, which did not assign any value to his ability to successfully communicate very complex ideas in collaboration with an interlocutor. My experiences as a research assistant collecting data on subjects in this manner combined with my lifetime of experiences being personally involved with close family members with communication disorders motivated me to develop a line of research that I feel is more humane and useful.

Conclusion

As I mentioned at the beginning of this chapter, I believe academic research is most compelling when the researcher is personally invested in solving a personal predicament. Throughout the chapter, I have allowed readers to see how the present study is a personal predicament for me. By sharing my own personal experiences and motivations for this research, and by introducing readers to the unique personalities that are in this study I have endeavored to entreat readers to also become personally invested in understanding communication with people with speech disabilities. In the next chapter, readers will see how the experiences described here have informed both the theoretical framework and the methods I have chosen for this study.

CHAPTER 4: THEORY AND METHODS

Theoretical Framework

Linguistic Theory & The Human Ability for Language

Although a great deal of linguistic research during the last century adhered to the dichotomy first conceived of as *langue-parole* by Saussure in 1915 (Suassure, 1983) and later re-appropriated by Chomsky (1957) as the *competence-performance* divide, there is a new recognition that to study performance *is* to study competence (Jacoby & Ochs, 1995). Rather than viewing language as a static *entity* in the mind, as an underlying and innate competence that then permits performance (or *use* of the competence), uniting the two into one and the same *process* is a growing trend in linguistic research in which I situate my own research (Lemke, 2006; Thibault, 2004; Kelso, 1995).

In this current research, I am not simply shifting my lens to view only the sociological aspects of language (an analytical argument); I am instead joining the ranks of those who turn the statement “the human language capacity is a social process” into an ontological argument: we now know that all aspects of language, even down to the firings of neurons that occur in response to stimuli, are inherently only active social events (Lemke, 2006; Thibault, 2004). I posit that the artificial separation between competence and performance that has dominated theoretical linguistics is actually reinforced by sociolinguistic work that avoids discussions of competence altogether by claiming to only study performance. To address this issue, I study language and social interaction while also taking explicit responsibility for helping to redefine our competence as performance rather than being complicit in further reification of the competence-performance

divide. Before I outline the details of how I work toward this new definition, I briefly explain the view of an underlying language competence (Chomsky, 1957; Carnie, 2002) and then build a case for how the prevalence of this theory is detrimental to the study of people with speech disorders.

The Traditional View of Language Competence in Theoretical Linguistics

The conventional line of thought that has guided theoretical linguistic inquiry and many consequent applications over much of the last century (Harris, 1993) is simplistically summarized as follows: humans are born with an innate ability to understand, process, and produce language. This ability resides in a defined and locatable area of the brain that exclusively manages language tasks and relies on input from the social environment only to set its very basic parameters and limitations, otherwise known as “constraints.” These constraints make up the system of rules that govern the hierarchical ordering of morphemes, the smallest possible units of meaning in a given language. This system of rules is known as the syntax of a given language. To theoretical linguists (Chomsky, 1957; Lakoff, 1988, 1992; Postal, 1988, Carnie, 2002), syntax is the engine of correct grammatical sentences, the underlying *competence* that enables our *performance* of language tasks. This language machinery in “the mind” somehow *generates* utterances based on this internal system of rules and constraints that define the limits of what we can do with language. And so, we have the *Generativist* paradigm (Carnie, 2002).

The notion of the pre-programmed computer is still used as a metaphor to illustrate the generativist position: “The underlying thesis of generative grammar is that sentences are generated by a subconscious set of procedures (like computer programs). These procedures are part of our minds (or of our cognitive abilities if you prefer)” (Carnie, 2002, p.5). The author of

this syntax textbook further suggests, “You can think of these rules as being like command lines in a computer program. They tell you step by step how to put words together in a sentence” (Carnie, 2002, p. 5).

Many linguists view this account of competence as highly problematic as our language competence, or ability itself, has come to be equated with the ability for syntax (Lieberman, 2002). Being able to place morphemes in grammatically correct orderings has become the measure of human language, while the ability to functionally communicate with language is relegated to being merely the implementation of this underlying competence. In a sardonic summary of how theoretical linguists proceed in their quest to define language, Agha (2006) stated the following:

First, redefine what the word language means, preferably fixating upon a fragment or feature of language—let’s say the concatenation system of language, its syntactic and phonotactic aspects—and call this fragment ‘language’ (or even ‘Language’). Second, redefine the study of this fragment as the study of some restricted type of data about it, let’s say the study of decontextualized intuitions about it. If you’ve done this carefully enough, you can now amaze and amuse your friends by pulling a vast number of rules and constraints out of the hat of introspectable intuitions. And, now, the statement, ‘the study of language is the study of constraints’ appears to be true. But a more accurate way of stating this truth is, ‘the study of decontextualized intuitions can isolate plenty of features of a concatenation system that appear as inviolable constraints to those intuitions (p.18).

Here, Agha is specifically criticizing how one small part of the process of language, the “concatenation system” is viewed as “Language” in theoretical linguistics. The way to study this concatenation system is to collect lists of patterns that happen to be common in languages and then consider these patterns to be fixed rules that govern our production of correct grammar. What theoretical linguists seem to ignore is that the framework in their minds that serves as the judge of acceptable language has itself been formed by social interactions over the entire evolution of our human race and during the entire lifetime of any linguist who has developed his sense of “right” and “wrong” language through enculturation into a particular social group of speakers.

Our unique ability to create and interpret meaning through linguistic and other semiotic means exists only by virtue of thousands of years of phylogenetic (species-level) socialized development and millions of complex social interactions during ontogenetic (individual-level) development. The human capacity for language simply does not exist as a final product of development but rather exists only as a process of continual adaptation to selective pressures with which each of us interact in our physical and social environments. There is no human language ability that resides in any human skull anterior to or independent of social interaction (Goodwin, 2004).

In defense of theoretical linguists I should point out that Chomsky, considered to be the originator of this approach, has made it clear that he is specifically not interested in language use or *performance*. He is only concerned with identifying patterns of constraints that would be used by a theoretical “ideal speaker-listener...in a social vacuum” (Chomsky, 1965, p.3). This approach is clearly motivated by logical positivist thinking, where the researcher holds all variables constant in order to focus on one aspect in a controlled environment.

In order to create a succinct and neat theory about the human capacity for language, theoretical linguists have necessarily had to abstract away from the messy errors, false starts, misunderstandings, pauses, and other variations inherent in talk-in-interaction. But as there is no such thing as an ideal-speaker listener nor a social vacuum, one has to wonder what good it does to provide such a theory that ultimately explains no language reality at all. It appears that theoretical linguistics is an extreme application of Occam's Razor, where in the quest for parsimony, we have wound up with absolutely no explanatory power. In summation, "This approach has led to a mountain of good data. It has not led to good theory" (Thelen & Smith 1996, p. 26).

To be quite clear in stating my position, let me say that there is nothing inherently invalid or wrong with studying syntax and then finding compellingly similar patterns of grammar throughout languages in the world. The problem arises because theoretical linguistics has served as the dominant paradigm for defining the human language capacity. In the next section, I examine how this limited definition of human language competence creates difficulties for working with people who have speech disorders, including my own father who is a primary subject of this study.

Competence and People with Neurogenic Speech Disorders

There are several ways in which this notion that language equals an underlying ability to do syntax, outlined in the previous section, is problematic for working with people with speech disorders. First, this paradigm leads researchers and therapists to look for, assess, and provide therapy for an elusive language capacity that is in the heads of individuals. This process can encourage a deficit perspective as the competence of people who are known to have brain damage are judged based on the area of the brain that is affected and the expected trajectory of a

particular disease's pathology rather than what they can actually do with language. Such an approach accords with the conventional biomedical tradition outlined in the literature review (Chapter 2).

Second, endowing a theoretical syntactical engine in our brains with exclusive proprietary rights over the creation of utterances has resulted in neglect of the power of communication that occurs through other semiotic means. Aggrandizing the power of hierarchical orderings of sound units diminishes the status of meaning negotiation that occurs in the interstices between human brains. This is a particularly salient issue in dealing with people with speech disorders because they may use compensatory strategies when their ability to produce syntactically "correct" utterances fails them. Often, they may rely more heavily on semiotic modes other than their phonological stream to make conversational contributions that are equally as complex.

Third, the generative linguistic paradigm promotes the idea that all well-formed utterances are formed in the syntax module in the brain of one individual and then transferred directly to the perceptual mechanisms of another. In this view, meaning and understanding occurs somehow and somewhere during this transfer process. Such an approach does not allow for collaboratively negotiated or co-constructed utterances that may have no "correct" grammar at all. As people with neurogenic speech disorders often do not create utterances that are grammatically correct (Goodwin, 2003; Schegloff, 2003), their speech partners may be called on to help them get their meaning across. In these instances, there is no one-to-one direct transfer of interpretable meaning, but rather co-constructed meanings.

Finally, the notion that we are all born with the basics for our syntax module rather than forming it as we go along through life leads to a belief that our language ability is a static entity,

the limits of which cannot be expanded nor improved upon during a lifetime. Believing that we have only this one unit of language ability in our brains also leads to the notion that once it is impaired, there is nothing to be done. The simple fact that people with speech disabilities are known to find alternative means of communicating calls for a new perspective that challenges this notion of language as a static entity. By redefining language, we can view alternative strategies as the evolution and development of new abilities rather than as lack of ability.

Language as the Process of Co-constructing Meaning

Redefining Language

In this dissertation, I work within a paradigm that rejects Cartesian dualisms such as competence-performance, comprehension-production, and mind-body. As I frame this study theoretically, I draw on research in sociolinguistics, social semiotics, and linguistic anthropology and work toward a new definition of the human language capacity with a humble acknowledgement that it is so complicated, we may never fully grasp its complexity.

As we now know that social action entrains the processes in the brain during ontogenetic development, that there are multiple feedback loops between how we interact and what our language capacity is at any moment, we can redefine language as a dynamic process, the limits of which are potentially infinite. We know there is no executive commander or programmer of linguistic action in the brain, no language acquisition device, indeed no entity that is physically specified in any way. Instead, the brain works in the same way as biological systems at all different scales: in a Darwinian act of natural selection. As we now know that nothing occurs in the brain that is not a result of our bodies ushering our brains through time, space and social interaction, we can begin to see the body as an open biological system affecting and affected by the environment. Our language capacity is quite literally defined only by how we use it

(Thibault, 2004; Lemke, 2006; Edelman 1987,1989; Thelen & Smith, 1996; Thelen, Kelso, 1995; Sporns & Tononi,1994).

Rather than imagining the human brain as a processor with discretely mapped spaces that control different cognitive competences, Kelso (1995) views the brain as an open and dynamic system. In his view, we can only view patterns and abilities as they play out in the dynamics of our interactions with the world. Kelso imagines the brain to be:

...a constantly shifting dynamic system; more like the flow of a river in which patterns emerge and disappear, than a static landscape.... This is an entirely different image from the brain as a computer with stored contents or subroutines to be called up by a program. In nature's pattern-forming systems, contents aren't contained anywhere but are revealed only by dynamics. Form and content are thus inextricably connected and can't ever be separated (p.1).

The inseparability of form and content Kelso mentions here echoes the inseparability of performance and competence discussed above. By uniting the mind and body both ontologically and analytically, linguists are able to study how people use all the semiotic means available to them to work toward intersubjectivity with interlocutors. In the next section, I discuss how embodied actors co-construct meaning in semiotically rich environments.

In this dissertation, I draw heavily on many different aspects of Goodwin's work (2006, 2004, 2003, a, b, c, 2002, 2000a, b, 1995). As mentioned in the literature review (Chapter 2), Goodwin views people whose means to communicate are severely limited as competent and significant social actors. In the following section, I focus on the analytical frameworks Goodwin uses in order to arrive at this conclusion. Although Goodwin uses the concepts described below to study the interactions of a person who has suffered a stroke, I adopt these same concepts for

application to analysis of my father who has been a long-time sufferer of Parkinson's.

Goodwin's line of research with stroke outlines many of the same techniques my own family uses to co-create meaning with my father who has PD.

Embodied Interaction

As an alternative to research that views the ability to communicate as "the disembodied manipulation of symbolic structures" (Goodwin, 2003b, p.1) Goodwin proposes that the brain is embedded in a body that is itself embedded in a consequential, structured setting and ongoing human interaction. The setting in which interaction takes place is "consequential" because it factors significantly in meaning making by providing semiotic resources that actors may call into relevance. It is structured due to the ways actors in the past have used the semiotic resources in the environment to create meaning. Over time, within particular groups of speakers, these meanings become sedimented, providing an additional layer of semiotic resources to draw on as objects and events carry particularized meanings for particular groups of people.

The specific term Goodwin uses to describe places where meaning-making can occur is "semiotic field," which he defines broadly as "diverse media in which different kinds of sign phenomena are instantiated" (Goodwin, 2000a, p. 1490). In a more detailed definition, Goodwin explains, "The term semiotic is intended to note the way in which signs are being deployed, while field provides a rough term for pointing to the encompassing medium in which specific signs are embedded" (Goodwin, 2000a, p.1494). In such social semiotic approaches,

There are no symbols, words, signs, texts, and so on, in the individual's head.

Rather, symbols, words signs and texts are dually semiotic-material artifacts that exist in the external world – the ecosocial environment –by virtue of somatic or extra-somatic processes of production and manipulation (Thibault, 2004, p. 51).

Like Goodwin (2004), Thibault (2004) rejects the notion that individual actors store and then transmit meaning. Instead, our bodies and the ecosocial semiotic environment mutually produce, manipulate, and construct one another.

Goodwin proposes that there should be no “analytic boundary drawn at the skin of the participants” (2003b, p. 11) as bodies and physical environments mutually elaborate and constitute one another. In Goodwin’s work, the body itself is a “dynamic, temporally unfolding field that displays a reflexive stance toward other coparticipants, the current talk, and the actions in progress” (Goodwin, 2000a, p. 1519). During interaction, participants use an “embodied stance” to create “participation frameworks,” to build mutual orientations to areas, objects, or events of interest (Goodwin, 2000a, p. 1496). Critically, the participation framework an actor creates takes into account the orientation of the interlocutor’s body as well. In order for to establish a participation framework, all interactants must have their bodies aligned in ways that allow them to both see what the originator of the action is referring to and so that they can demonstrate that they are themselves active participants.

Once interactants have defined a participation framework with their body orientations, they can further specify an area or object of interest by pointing to what Goodwin calls a “domain of scrutiny” (Goodwin, 2000b, p. 73). Goodwin defines the domain of scrutiny as “a region where the addressee should begin to search for something that might count as a target” (p. 73). The target is generally understood to be the specific thing, place, or event of interest to the pointer or speaker. Often in interaction, however, the referent of an interlocutor’s pointing, speech, or body orientation is not immediately recoverable: there may be several candidate targets within a domain of scrutiny. Interactants may go through a process of negotiation in order to determine the intended target. In addressing this phenomenon, Goodwin introduces the

term, “activity framework” to explain how each of the different targets are themselves connected in complex ways to particular activities. This becomes relevant in Goodwin’s work when he is trying to figure out what Chil (Goodwin’s father and the subject of much of Goodwin’s research) is pointing to on the breakfast table (the domain of scrutiny). There are several possible targets on the table, such as an assortment of pastries, a box of Kleenex, a newspaper, a plastic cup, silverware and so on. These potential targets are all linked to various different actions: eating, blowing one’s nose, reading, drinking, cutting through food. These are considered to be the activity frameworks. In order to accurately understand Chil’s meaning, Chuck must figure out the correct action that Chil is interested in as it is linked to these objects. (Goodwin, 2000b). As Chuck provides the words for Chil, he suggests several of the items and actions, which he refers to as alternative guesses (co-constructing meaning) or candidate utterances.

Co-participants in interactions must keep track of all the different activities including gestures, sounds, body orientations, and gaze as actions unfold. Goodwin (2000a) calls this process, “reflexive awareness,” an “ongoing analysis of how [a participant’s] recipient is positioned to co-participate in the interactive frameworks necessary for the constitution of action.” (p. 1503). This awareness is not simply “an ‘interior’ element of the mental processes necessary for defining action” but is a “public, visible component of the ongoing practices used to build action, something that leads to systematic, relevant changes in the shape of the action” (pp. 1503-1504).

Co-construction of Meaning

Throughout Goodwin’s work, those involved in conversational interaction are “co-participants” and all meanings are built collaboratively through multiple semiotic modes. Meaning is co-constructed between at least two interactants rather than being formulated in one

mind and then directly transferred through perfect grammar to another. In conversations with Chil, all meaning is co-constructed as he embeds his gestural and limited sound repertoire contributions within the ongoing talk of others (Goodwin, 1995, 1996, 2002a, 2004). Even pointing for Goodwin is a co-construction, as it is a process that often entails negotiations to recover the intending target. (Goodwin, 2002a, 2003c, 2004). In this dissertation I draw on multiple definitions and usages of co-construction in order to understand how my family collaboratively makes meaning with my father. I now turn to additional definitions of co-construction that I draw in order to frame this study theoretically.

Jacoby and Ochs (1995) refer to co-construction as “the joint creation of a form, interpretation, stance, action, activity, identity, institution, skill, ideology, emotion, or other culturally meaningful reality” (1995, p. 171). This is an admittedly broad definition that implies all genre of activity, ideas, and cultural forms can be co-constructed. In Finnegan’s (2002) definition that is more specific to communication, she states that, “Communicating is not a once-and-for-all transfer of some referential content, but develops as the interactors jointly and severally co-construct the process” (p. 7). These definitions of co-construction all accord nicely with the view I outlined earlier in this chapter of language as a social process rather than a static entity.

To better understand how the notion of co-construction frames my study, I now turn to a brief history of the term. In explaining the roots of the concept of co-construction, Jacoby and Ochs (1995) note that co-construction began as a notion in “child language studies, soviet psychology, literary theory of the Bakhtin Circle, ethnomethodology and Conversation Analysis, and linguistic anthropology” (p. 172). In child language studies in the 1970’s researchers found this notion particularly apt for describing the interactions between children and their caregivers,

who “compose propositions across turns and speakers” (p. 172). Researchers noticed that children often begin statements but then rely on elders to help them finish. Children and their caregivers are seen to “jointly accomplish the production and interpretation of utterances” (p. 172). This type of co-construction is often called expansion. I investigate in great detail how my family jointly produces utterances with my father in Chapter 6.

In their interpretation of ethnomethodology, Jacoby and Ochs (1995) interpret Garfinkel as viewing “sense-making” as an interactional affair, where utterances are understood “crucially because others are filling in the common-sense understanding entailed in the situation at hand” (p. 178). In this dissertation I analyze the co-construction of meaning using applied CA and discourse analytic tools, joining other researchers who “use CA to focus on microgenesis of co-construction over the span of interactional time...examin[ing] co-construction through a sociologically and linguistically tuned microscope” (p. 179).

The Process of Co-Construction and the Role of Caregivers

It is only through the framework of co-construction that we can view people whose speech is severely hampered as significant conversational interactants. The interactional emphasis entailed in the notion of co –construction highlights how people with neurogenic speech disorders can be positioned as competent only through the cooperation and hard work of those who care for them the most. In order to study how people with disabilities accomplish successful communication, it is necessary to examine the process of co-construction with family caregivers. Before concluding my discussion of co-construction, I turn to a brief explanation of the role of family caregivers as a way of demonstrating how extraordinary their efforts to help a family member communicate are in the face of all the other burdens of caregiving.

As medical advances allow those with degenerative diseases to live longer, many families are finding themselves in the position of needing to care for loved ones in their homes for extended durations (Poulshock, 1984). As researchers have recently begun to study the mental and physical condition of caregivers, the many relentless burdens of caregiving are coming to light. For example, Fernandez et al. (2001) and Happe and Klaus (2002), have examined the relationship between sleep fragmentation and depression in caregivers of people with Parkinson's. As Parkinson's patients often suffer from tremors, Restless Leg Syndrome, and generally fitful nights, caregivers often find themselves on duty throughout the night (Fernandez et al., 2001). People with Parkinson's may also need assistance for nighttime urination and to turn over in bed. This sleep disturbance has been shown to result in feelings of overwhelming fatigue and depression in caregivers (Happe & Klaus, 2002). Aarsland et al. (1999) and Thomassen et al. (2002) have further concluded that the elevated levels of mental disturbance in a person who is cared for in the home environment can lead to depression in the primary caregiver. Caregivers are deeply affected by their added physical duties and the concomitant emotional effects of caring for a family member who also has mental disabilities. Aarsland et al. (1999) have also demonstrated that the ultimate hospitalization of people with both Parkinson's and Alzheimer's depends more on the state of well-being of the caregiver than the actual stage of the disease exhibited by the person with the disorder (Aarsland et al., 1999) According to Aarsland et al., there is a point at which caregivers' mental and physical health is so affected that they have to make the difficult decision to place the loved one in another's care in order to regain their own health.

Clearly, the effects of full-time caregiving duties for people with Parkinson's are dramatic. I include this section to demonstrate how difficult the role of the caregiver can be.

Although this dissertation focuses on the ways in which the members of my family (who are also part-time and full-time caregivers) help my father to communicate, I feel it is necessary to acknowledge that our co-construction of meaning in conversations with my father is only one of the many tasks my family undertakes to help him remain a significant social actor. While I place a great deal of emphasis throughout this dissertation on redefining people with disabilities as competent, it is important to view my family's interactions through the lens of co-construction, thereby acknowledging the tremendous lengths my family members go to in order to position my father as a competent speaker.

Concluding Remarks on the Co-construction of Meaning

The notion of co-construction encourages analysts to valorize the contributions to communication that come through multiple semiotic means deployed within a semiotically rich environment rather than ascribing the primary responsibility for making meaning to the hierarchically ordered phonological stream. In questioning whether or not we actually need a formal theory on meaning making, Lemke (2006) states that,

We need a theory because we already have one. If we don't formulate explicitly our ways of making meaning in particular contexts, the meanings we make will be governed automatically, by default, by the limiting meaning systems of our narrow communities, even when we are not aware of this. (p. 157)

The theory we already have is theoretical linguistics. Lemke (2006) explicitly calls for codifying the processes that we use to make meaning in real-live interaction or else the theory we already have will serve as the default construct.

Working to redefine language as the co-construction of meaning allows us to begin to view our competence as enacted through communication with others rather than stored in our

brains. Lemke reminds us that, “Neither in its material origins in the processes of the brain, body, and community, nor in its uses for the making of meaning does it stand on its own” (Lemke, 1995, p. 8). Language is only a social process. Indeed,

to study language behaviour, discourse, and social interaction – which some might call linguistic or communicative performance – *is to study communicative competence*, not as an abstract construct or model, but as it plays out in all its incredible complexity as people go about managing their identities, their relationships, and their lives. (Jacoby & Ochs, 1995, p. 179)

Only by redefining the study of language performance as the study of competence can we as social linguists forge a view of physically limited social actors as competent in the ways they do manage to make meaning with others in the world. As I study how my own family co-creates meaning with my father, I apply this notion that performance is competence so that I can analyze what we are doing rather than highlighting what we are not able to do.

Research Design and Methods

General Design

I designed this research based mostly on Goodwin’s work observing his father (Chil) in family conversations (2006, 2004, 2003a, b, c, 2000a, b, 1995). As the primary focus of my research is to discover how my family co-constructs meaning with my father despite the severe impairment of his ability to communicate through a vocal phonological stream (see chapter 1), I needed to capture the visual aspects of communication through a video camera. Following Goodwin, I videotaped naturally occurring talk in my family’s home as the members went about their daily activities. This natural and comfortable setting was critical to my research design as I am specifically interested in analyzing functional aspects of language rather than attempting to

elicit utterances from pre-determined questionnaires or assessment protocols. As I outlined in chapter 2, there is no shortage of research that uses questionnaires and assessment protocols to analyze the speech of people with PD. Generally this approach is in pursuit of cataloging what is wrong with the subjects' speech. I instead designed this study to capture the many ways in which my father and his family *are* capable of communicating.

To be sure, there are certain ethical concerns involved with using the video camera to collect data. Heath and Luff (1993) point out, for example that anonymity cannot be easily preserved when analyzing and presenting the findings of video data. This issue is particularly salient when the research subjects are people with disabilities who may already carry a particular “stigma” (Goffman, 1964) or negative stereotype in our society. Despite the potential drawbacks of using the video camera, I decided that the potential benefits outweighed the concerns. Allow me to give some personal insight that may help explain why I felt videotaping would not be a major issue for my father or the rest of my family.

As my father has participated in clinical pharmaceutical trials through Emory University over the last eleven years, I have often questioned him as to why he wanted to submit himself to experimental drug combinations. Dad's responses have varied somewhat over the years, but he has always seemed to express multiple motivations including the ability to receive cutting edge treatment, the exposure to world-class doctors, and a sense of obligation to further research and work toward a cure for PD.

Also, over the years, my father has agreed to participate in public arenas where he would be examined by groups of people interested in knowing more about his disease. For example, he agreed to attend a course in Communication Sciences and Disorders where the instructor used him to illustrate how a speech therapy session might take place. After the professor of the class

finished the physical examination of his speech apparatus, he read a speech sample out loud with considerable animation and then gave the class a spontaneous lecture on how PD affects the brain and how his medications are designed to be transportable across the blood-brain barrier. When Dad's dyskinesias kicked in, his legs and arms flailed somewhat and his speech was becoming more incomprehensible. At this point, Dad carefully explained what was happening to his body and why. Throughout the class, Dad continually made jokes, mostly at his own expense, to lubricate the entire interaction. Rather than being embarrassed of his disease, Dad came to class to teach the students about PD.

Importantly, in arranging the class agenda beforehand with the professor, we had imagined that it would be very difficult to elicit speech from my dad in front of such a large group (nearly 30 students and professors). The professor had expected to do a lot of questioning to cajole my dad into talking about his disease. Instead, Dad seemed to take the floor, pursuing his own agenda of educating others about the biochemistry and the physical and emotional struggles of PD.

Dad has also served as a trial patient at my husband's Chinese Medicine School, where the intimate details of his body, daily routine, and even psychological history were discussed openly in front of several doctors and students. In all of these instances, Dad has always been very eager to help others understand his illness better. At no point has he appeared too ashamed of the state of his body to make his difficulties public. Because Dad is so open with his disease and willing to further any research on PD, I felt asking him to make his identity and image public would not be troublesome or exploitative.

In order for my father to participate in all of these trials and classroom experiences, my mother has had to fully support these efforts by arranging schedules and ferrying him to his

appointments. Despite the many complicated medicine schedules and the organization she has had to do over the years to take off work to drive Dad to Atlanta, or Athens, GA or Asheville, NC, my mother has displayed unfailing dedication to both my father's well-being and the rigid guidelines for drug trials. She has always demonstrated an unwavering support for the advancement of research and education in PD. Because of her cooperative attitude toward all the research conducted on my father through the years, I felt asking her to participate in this study openly would not be problematic.

During the embryonic stages of designing this project, I talked with my parents about the purpose and implications of carrying out such research. I asked if their identities could be made public and they agreed. I also asked my husband, my brother, and his girlfriend to participate so that I could collect a comprehensive data set of the communication strategies developed by different family members. Throughout the analysis, all real names are used. Because I am writing from my first person point of view, my parents carry the titles of "Mom" and "Dad" rather than their first names. All parties have signed consent forms developed in accordance with the University of Georgia's Institutional Review Board regulations on research involving human subjects (see Appendix D).

Data Collection

In order to adequately capture the collaborative meaning making that occurs in conversations with my father, I videotaped conversational interactions at my parents' home from April, 2005 until June, 2007 every time I went home to visit. In an effort to collect data that is as genuine as possible, I tried to allow the camera to blend into obscurity in the room. While all parties were always aware that the camera was filming, I generally placed the camera in ways that it would not be prominent in the room or so close that it would crop out contextually

relevant features of the physical environment. I made my best efforts to create a social atmosphere that allowed my family members to feel comfortable acting in their usual manner. I assured all participants that the camera could be shut off at any point and let them know they had the right to ask me never to show a particular segment of potentially compromising data. While there were certain occasions on which my mother asked for me to shut off the camera, there are none so far that anyone has asked that I delete or keep private. I also made conscientious efforts to exclude individuals from the camera frame who asked not to have their image included due to their own perceptions of inappropriate attire or inadequate physical preparation for the videotaping process. The instances where I did turn off the camera or modify the camera framing will be discussed in greater detail in my section entitled, *Difficulties and Limitations* at the end of this chapter.

While some researchers believe that video research can greatly intrude upon the social reality that is being observed (Heider, 1976; Weimann, 1981), I adopted Lomax and Casey's (1998) viewpoint that although videotaping may alter certain aspects of the interactions, these changes are acceptable as long as researchers include critical, reflexive discussions of the influences of the camera. Lomax and Casey (1998) assume that there will always be "reactive effects" on behalf of the participants as the process of using a video camera "helps socially construct and produce the data that is collected" (Lomax & Casey, 1998, p. 2).

The reactive effects of my videotaping are particularly observable on the first tape of data I recorded (see Appendix C, 4.22.05), when Dad and I are sitting in the living room together engaged in conversation. After about three minutes, I answer a short phone call from Mom. When I hang up the phone, Dad instructs me to "take it back." At first, I cannot understand what Dad is referring to and I ask for several clarification requests. After many negotiations, I

eventually understand that Dad wants me to rewind the tape back to before Mom's phone call. Although I try to explain to Dad that this imperfect interruption to our ongoing conversation does not really matter as I am just trying to keep the camera rolling, he still does not seem to understand. He continues to plead his case out of concern for "lost tape." Dad especially seems to think that our conversation about the lost tape is wasted space and should be re-recorded to capture better conversation data. I take efforts here to re-explain the point of the research and it is unclear if he understands during this conversation. Interestingly, upon comparing Dad's speech on this tape to his speech on others, it is very obvious that he was trying to speak carefully for the camera. He takes more effort on this tape to enunciate clearly and to phonate than on any of the other tapes. Here, he was using his understanding of what my research purpose was to "put on a better face" for the camera (Weimann, 1981, p. 303). It is important to note that I only witnessed this effect on this first video (Appendix C, 4.22.05), which indicates that Dad did eventually understand that I needed him to talk as he normally would.

What I find to be most remarkable about this first hour of footage is that when I analyzed the data and coded for the different alternative strategies we used to co-construct meaning, I only found a few brief examples of scaffolding. As Dad thought I would be analyzing how well he speaks, he was using careful speech strategies. Throughout this tape, I seemed to be able to understand most of what he was saying based primarily on his phonological stream. Although the presence of the video camera did affect my data collection, it was not necessarily a negative result. This one hour of footage suggests that perhaps clear speech techniques researched by Goberman and Elmer (2005) and recommended as means for speech therapy in PD could be useful.

For the most part, I do not feel that the presence of the video camera impeded my collection of useful data on family conversations. Based on my insider's knowledge of the ordinary workings of my family, they mostly appeared to act the same as they would without the camera's presence. Prominent throughout the data are situations where my videotaping coincides with Dad's desire to listen to classical music at extraordinarily high volumes. In one instance, the CD player is actually placed directly next to where I have set up the video camera. As I go to turn down the music just slightly because it appears to me that Dad has fallen asleep and as I know the music will make recording of any conversations inaudible, Dad immediately sits upright and gives me a look of disdain. I am obligated to turn the music back to its original volume. In instances where Dad wants to listen to music even though he knows I am trying to record, the music always takes priority. In my interpretation, this serves as evidence that Dad is not compromising his normal activities for the benefit of the camera.

In support of my view that the video camera did not hinder the collection of useful data, I draw on Wiemann (1981), who posits that most researchers interested in recording social interaction believe that subjects do not seem to modify behaviors that are not under conscious control during videotaping. Included in these "out of consciousness" behaviors are all gestures, gaze, pauses, and timing in interaction (p. 302). Weimann's empirical research on videotaping procedures supports this argument. As I was mostly interested in examining *how* we make meaning rather than *what* meanings we make, I feel Weimann's (1981) proposal is relevant. While I think it is easy for subjects to change what they are saying (the meaning) in order to "put on a better face," I do not think it is possible to drastically and intentionally change the strategies we use to communicate, which seem to come automatically. The consistency with which the same patterns of strategies emerge throughout the data also serves to reinforce this notion that

the strategies we deploy are relatively unaffected by the presence of the video camera. Finally, I noticed throughout the data set that my family does actually seem to feel comfortable talking about all genre of topics in front of the camera. For example, Dad feels uninhibited enough to talk about his bathroom routines and he does not seem to take efforts to create an image of a family with no conflicts. In fact, Dad and I seem to carry on our business like most fathers and daughters, laughing at private jokes and also raising our voices to each other when we disagree.

Over the two years and two months of recording family activities, I collected just over 23 hours of footage. When I went home for family visits, I took my camera and tried to capture some tape during each trip. It is important to note that the time periods during which it is possible to collect data with my father are very limited by his schedule, the disease, and the activities he is able to participate in. For example, the medicine routine he adheres to only put him in the “on” state for a couple to several hours per day. Much of the rest of the day he sleeps. During these “on” hours, we attempt to accomplish all kinds of things including running errands he needs to do or taking dad out to eat. As managing Dad in his wheelchair in public is demanding and consuming, I did not feel comfortable also trying to videotape during these trips. Additionally, the human subjects regulations for videotaping in public places are extremely complicated. Even when we are not out doing errands, I am generally occupied doing chores for Dad at home. The time and attention needed to care for my father’s needs thus have somewhat limited my data collection. Below is a chart of the data I collected, which reflects the videotaping I did in my parents’ home.

Table 1. Data collected

D=Dad; M=Mom; C=Charles, A=Amy; AD=Andrew, K=Karolyn

Date	Total Time (h/min/sec)	Activity	Location	Participants
4.22.05	00:26:30:	Careful conversation	living room	D, A
10.30.05 A	0:1:02:00	searching the internet closing the pool	music room outside	D, M, C, A
10.30.05 B	01:02:00	closing up the pool assembling antique lamps	Outside music room	D, M, C, A
2.11.06	00:47:20	Dad's birthday dinner	Kitchen	D, M, C, A
4.16.06 A	01:01:00	breakfast lunch	Kitchen Kitchen	D, AD D, C, A
4.16.06 B	00:17:06:	arranging and playing records and cds	music room	D, A
5.24.06 A	00:46:00	searching for Dad's memory box	music room & living room	D, C
5.24.06 B	01:02:00	Getting opera on the TV	living room	D, A
7.04.06	00:42:25	Breakfast	Kitchen	D, M, C, A
7.05.06	00:38:46	breakfast swimming in the pool	kitchen outside	D, C, A
7.26.06	01:02:00	ordering CDs online	music room	D, A
8.26.06	01:02:00	breakfast	Kitchen	D, C, A & M (voice only)

10.12.06 A	01:02:00	feeding Dad putting cassettes away	living room music room	D, A
10.12.06 B	00:11:54	eating, watching opera	living room	D, A
10.25.06	00:32:59	Dinner	Kitchen	D, M, C, A
11.07.06	00:31:35	Dinner	Kitchen	D, M, C, A
11.08.06 A	01:00:00	Dad dictates X-mas letter	Kitchen	D, A
11.08.06 B	00:49:06	Putting cassettes away	music room	D, A
11.08.06 C	00:34:17	Dinner	Kitchen	D, M, C, A
11.23.06	00:58:58	breakfast	Kitchen	D, C, K, A
11.24.06	01:02:00	breakfast	Kitchen	D, M, C, K, AD, A
11.25.06	00:56:08	breakfast	Kitchen	D, M, C, A
2.09.07	00:8:51	Dad on the phone to Pippa	Kitchen	D
3.13.07 A	1:02:00	sorting through cassettes reading a letter outloud	kitchen kitchen	D, C, A D, M, C, A
3.13.07 B	00:31:10	continuing to read letter	Kitchen	D, M, C, A
3.16.07	1:02:00	dinner rearranging CDs	kitchen music room	D, M, C, A D, C, A
4.08.07 A	1:02:00	fixing Dad's wheelchair having tea	music room kitchen	D, A
4.08.07 B	00:58:49	Dinner	Kitchen	D, M, C, A
6.09/10.07	1:02:00	dinner	outside	D, M, C, A

		brunch	outside	D, M, C, A
6.10.07	1:02:00	Dinner	Outside	D, M, C, A
TOTAL	23:08:00			

As can be seen by looking at the chart, most of the conversations I videotaped occurred during meal times. This is similar to a study conducted by Bauer and Kulke (2004) where researchers videotaped 21 hours of footage at dinnertime. As is the case with many families, meal times provide an opportunity for us to catch up on the happenings in each other's lives through casual conversation at the table. The length of my family's meals is generally between 30 minutes to an hour, as seen in the chart. Primarily, my data collection took place in the kitchen, even when we were doing activities other than eating. I placed the camera either on the nearby kitchen counter or perched it on the top of the kitchen cabinets, depending on the configuration of the participants at the table. Difficulties with filming during dinner will be discussed in the next section.

Other physical settings for the videotaping include: the living room, my father's music room, and outside around the back of the house. In the living room and music room, I placed the video camera on the back or the arm of the sofas, and outside I mostly used a tripod to hold the camera. On a few occasions, my husband was present to help with the videotaping. His efforts proved to be extremely useful, as he was able to change the position of the camera as my father and I moved out of the frame. His re-positioning of the camera resulted in a greater amount of useable data as there were no breaks in capturing our actions as we moved. My husband remained quiet while moving or focusing the video camera, which leads me to believe that his presence was not affecting the data collection.

The activities our family was engaged in during the videotaping include but are not limited to the following: searching for family records such as birth certificates and passports, rearranging piles of CDs and cassette tapes, searching for records to play, searching for and buying musical CDs online, maintaining the pool and landscaping the surroundings, taking my father for a swim in the pool, feeding my father, watching opera with my father, and doing a number of inside chores for my father. As these activities are quite varied, the data collected provides a range of different communication strategies to analyze.

Throughout the data there is a wide enough variety of family members to find patterns that are common independent of who is speaking with Dad. While I have noticed some minor differences in strategies from person to person, this will not be the focus of the present analysis.

Difficulties and Limitations

As with all methods of data collection, capturing the video footage for this research project suffered drawbacks and limitations. The problems I encountered were related to: complying with requests to turn off the camera, positioning of the camera, sound and microphone issues, difficulties inherent in recording during mealtimes, and Dad's general habits. In this section I discuss each of these difficulties and describe how this may have limited my data collection. I then discuss ways in which I feel these problems could be rectified in future research projects where videotaping is involved.

As I mentioned in the previous section, I videotaped our interactions as frequently as possible during my visits to my parents, but I did not want my research to be so invasive that it prevented my family from feeling comfortable living in their own space. This was not for the sole purpose of collecting naturally occurring data, but also so that my family did not feel the research was negatively impacting our relationships or impinging upon our scarce family time

together. This was a matter of respect for my family as much as an underlying methodological decision for collecting data that was as natural as possible. There were only two instances when a member asked me to turn off the camera so they could feel more comfortable. One of these occasions resulted in a loss of what could have been very fruitful data for this and other research projects.

This loss of potentially useful data occurred during our family's Easter meal together in 2006. My mother wanted to feel more private and not on display during the meal, so she asked me not to videotape. After I removed the camera, the natural flow of conversation during this meal turned to a rich discussion of the problems my parents were having with getting their new insurance plan to pay for my father's Parkinson's medications. My mother described the long afternoons she'd spent on the telephone with pharmaceutical companies, the insurance provider, and the company my father retired from just trying to get them to send my father's medications to him. This topic was of such great personal interest to my father that he became a lively contributor to the conversation, filling in the gruesome details of the battles they'd had with the health care systems. My father was more deeply engaged in and animated during this conversation than in any of the other conversations I have on videotape. Although this interaction could have provided excellent material for analyzing a number of different aspects of conversation, non-compliance with my mother's request or coercing her into letting me start the video camera would have not only violated my human subjects regulations, but could also have engendered negative feelings toward my research in general. In addition, starting the video camera may have made my parents temper the passionate tenor of the conversation or could potentially have shut down the conversation altogether.

The next problem I encountered is related to the positioning of a stationary camera. Attempting to capture such a range of activities, both indoors and outdoors presented some difficulties. First, as I was often very involved in doing things for and with Dad, including wheeling him around, it was very difficult to keep up with repositioning the camera. The negotiations required for me to both attend to the task Dad and I were trying to get done and to the view of the camera became a very complicated balancing act. Often, I would wheel Dad over to an area where he wanted to be and then have to interrupt the flow of our activity to go back across the room and move the camera. If I could not break away immediately from our activity, the camera remained poised to capture only sound until I could manage to get over to it. In some cases, this resulted in a loss of data. Such losses occurred on the videos labeled 4.16.06 and 3.16.07 (see Appendix C).

The position of the camera in relation to participants' bodies was also an issue in cases where in going about our daily business, we actually blocked relevant actions and objects in the environment from the camera's view. Regardless of conscious efforts to avoid this, in some cases this problem was unavoidable. For example, on the tape labeled, *10.30.05 B* (see Appendix C), as I am busy trying to sort through boxes of lampshades, I block the camera and prevent a full analysis of the actions my Dad and Charles are engaged in.

Closely related to problems with the positioning of the camera are problems I experienced in trying to acquire clear sound. On occasion, in order to capture the full range of actions of participants, I needed to move the camera back away from them. As I was relying on the microphone on the video camera itself, this sometimes created difficulties in capturing participants' speech clearly. Loss of sound due to the camera being placed far from the activities happened very infrequently throughout the data set and was most pronounced when I recorded

outside. The movement of participants' bodies through a greater range of space forced me to place the camera at a great distance from participants. This occurred on 10.30.05 B, (Appendix C) when we were outside trying to close up the pool for the winter and on 7.05.06, (Appendix C) when Charles and I took Dad into the pool to swim. The sound is obscured by distance only temporarily, during times when participants were speaking in lower tones than normally. Although I was aware this placement would potentially result in loss of sound, I also felt providing external microphones to capture the sound more closely could create its own set of problems, such as intruding more overtly into the participants activity spaces, thereby perhaps changing their behaviors, or creating difficulty in synchronizing sounds with video during analytic stages. I did decide to try moving the camera closer to the participants, which on one occasion (10.30.05 B, Appendix C) resulted in a loss of data that is integral to understanding the actions that followed. As I unplugged the camera to move it, Dad spilled an entire jug of chlorine on the ground. The actions that ensued are analyzed in my third findings chapter, (Chapter 7, transcript entitled, *Pool Sharks*) but I have had to rely on informal participant checks where I asked participants to recall their versions of what happened while the camera was off.

Other issues with capturing clear speech resulted from interference with other environmental sounds. For example, sometimes it is difficult to hear speakers because of normal sounds of the outdoors, such as traffic, or general kitchen sounds before, during, and after mealtimes. I should note that although these sounds made analysis slightly more challenging, I do not feel like they were invasive enough to change or prevent analysis altogether.

The main problem with acquiring good sound came as a result of my father's favorite activity: listening to music. As an avid classical music fan, Dad likes to tune into the most nuanced details of what he is listening to and does not approve of only having music playing as

background to another activity. During several of the tapes, the activity Dad chooses to do is to listen to music. This occurs twice on 4.16.06 A 10.12.06 A, 10.12.06 B, 11.23.06, and 4.08.07 (see Appendix C). These different occurrences have different effects on the data. For example on 4.16.06, Dad and my brother Andrew are sitting at the kitchen table listening to music and occasionally talking. Understanding their conversation is virtually impossible. Other times, I simply turn off the camera when I realize it is futile to video record with this added din. This resulted in less data acquisition than I would have otherwise captured, but turning off the music instead was not an ethically nor socially acceptable option.

A problem that is inherent in trying to record conversations with my father during mealtimes that is unrelated to the placement of the camera and the sound capturing ability occurred due to the specific disabilities associated with PD. The attention and concentrated effort Dad needs to dedicate to the processes of eating and drinking often do not allow him to participate fully in conversations. This effect is particularly salient on 11.07.06 and 11.08.06 (see Appendix C). His participation during different mealtimes varies greatly over the data set due to various reasons such as his medication schedule, his general mood, the people present, the topics of conversation, and even the types of food we are eating. Overall, I found that Dad's participation in conversations is highest throughout the data when he is involved in and especially when he is in the position of directing others' activities and chores.

The last difficulty I will discuss relates to Dad's medicine schedule. One of the major side effects of Dad's cocktail of medications is that they induce sleep during the day. Even when Dad is in the middle of breakfast or another activity such as watching TV, listening to others' conversations, or watching the flurry activity around him, Dad can fall asleep with near narcoleptic immediacy. At times, this makes it impossible to collect conversation data with his

involvement. This is most noticeable on 5.24.06 and 10.12.06 (Appendix C) when Dad falls asleep while the camera is still running.

Also related to Dad's medicine schedule are problems that occur when his medicine has worn off completely. While this generally results in his non-participation in conversations, on particular occasions when he is in the "off" state, data collection can be enriched. For example on 6.09.07 and 6.10.07 (Appendix C), Dad is in a severely poor physical state. On these occasions, Dad's physical status engenders very rich data as my mother, Charles, and I are forced into doing tremendous amounts of scaffolding in order to understand his utterances. Over the years of experiencing fluctuations in the efficacy of Dad's medicines, I have noticed that in general Dad's interlocutors tend to create more utterances than him when his medicines are not working. Rather than viewing this as a drawback, I view this as an opportunity to understand our strategies when he is in the most drastic physical state.

Most of the limitations I have mentioned with the process of videotaping are not problems I could or would want to change. For example, even though allowing participants the right to ask me to stop recording results in losses of data, I feel it would be unethical to deny them this right. Also, the trade-off between capturing the full range of participants' actions and not capturing certain details of participants' utterances is an occasional limitation I am willing to accept, as my theoretical approach here values multimodal communication. The other limitations all have to do with the nature of people's daily routines, such as Dad's medicines, his changing abilities, and listening to music. These are all activities I would not want future research to impinge upon.

The one methodological approach I feel I could change for the better would be to either install motion-sensing cameras in a major site of family action, such as the kitchen that would

adjust to follow the participants' activities. Alternately, I could solicit camera help from family members or other people who may be present to videotape. In these ways, I may be able to prevent data loss from trying to participate in activities while also managing the video camera. Nevertheless, the data I collected allows the reader to observe a wide array of interactions and communication strategies that extend over multiple locations, participants, activities, and times.

Data Analysis

Methodology

In order to analyze the conversation data I collected, I used a hybrid of Applied Conversation Analysis (CA) and Discourse Analysis (DA). Before describing the details of how I carried out my analysis, I give a brief explanation of the major differences between the two approaches. Then, I tell what methods and ideologies I adopted from each of the two explain why I chose to hybridize the two approaches in order to reach a more complete analysis.

Conversation Analysis developed as a more specific line of inquiry within the alternate sociology presented by Garfinkel's ethnomethodology (Goodwin & Heritage, 1990). In creating ethnomethodology, Garfinkel was attempting to re-orient sociology to the study of small-scale phenomena rather than continuing Parsonian trends of generalizing, large-scale theorizing on social events (Heritage, 1984). At the roots of ethnomethodology and therefore also CA is a firm conviction to studying participants in their own terms rather than applying social categories of action, character types, status roles, or historical context to interactants *a priori* (Heritage, 1984; Korobov, 2001).

Early research in CA sought to outline the systems all ordinary interactants use in conversation on a daily basis. Researchers identified and reported on such patterns as turn-taking systematics, repair techniques, and sequential organization of talk (Sacks, Schegloff, & Jefferson, 1974). This focus on participants' procedures of conversational action is considered to

be “pure CA” (Have, 1999), having no broader interest than developing a better understanding of conversation for its own sake.

At present, there are a growing number of researchers who apply the already well-established body of literature on CA to the study of specific social phenomena. Researchers in fields such as anthropology, linguistics, psychology, sociology, and health professionals find applied CA useful. In an explanation of the differences between applied and pure CA, Have (2002) states that now,

CA can be done as a ‘pure academic pursuit, studying such procedures in themselves, or it can be done as an ‘applied’ discipline, to study how quite general ways of organizing talk can be used in actual situations to accomplish whatever is the local agenda, including various institutional tasks. (p.1)

In applied CA research, CA becomes a tool; it is a means to an end rather than an end in itself.

While discourse analysts use many of the same concepts and methods as CA (both pure and applied), DA grows out of a social theory that has a stated concern for the interplay between social systems and individuals’ actions. As a result of this fundamental interest, discourse analysts are generally interested in studying conversational interactions for some specific situation, as an applied practice. Discourse analysts such as Gumperz and Hymes may draw heavily on Ethnomethodological literature, but they “...go beyond ethnomethodology to consider these patterns as embedded in complex cultural practices” (Heller, 2001, p. 255).

The most widely debated and pronounced difference between these methodologies is the way researchers using CA or DA invoke context. As I mentioned above, pure CA researchers have a stated dedication to studying participants in their own terms rather than imputing social categories or historical contexts to participants that are exogenous to the specific interaction at

hand. Researchers performing pure CA are interested in uncovering conversational techniques, strategies, and patterns that are employed by all ordinary speakers, irrespective of the social context. As discourse analysts are explicitly interested in studying how social systems and individuals interact, they tend to study discursive action as it relates to other social constructs. This purpose necessarily entails describing and bringing to bear on analysis contextual information about interactants. While this process of including context may be viewed by some pure CA practitioners as inappropriately imputing social categories, some discourse analysts argue that they are allowing the participants to “speak for themselves” rather than assuming categories exist (Rymes, Souto-Manning, & Brown, 2005, p.196).

The narratives I have included in this dissertation (in the Prologue, Chapter 3, and Chapter 7) are one way that I bring additional contextual information about my family to my readers. The stories are of course, written as I remember the events and may affect how readers interpret the action shown in the transcripts. I argue that these narratives serve to situate and explain my epistemic stance as a researcher, a subject of research, and a daughter. By framing my research through the narratives and discussions of my personal experiences, the readers are able to know how I know what I know about what is happening in the transcripts and can examine my findings from a more insightful stance. The narratives provide windows onto the contexts that frame the interactions portrayed and analyzed in this study. I consider this inclusion of additional background information on and my family and myself to be one aspect of a Discourse Analytic approach that I bring to my dissertation.

While I base this dissertation on the work of Goodwin, (2006, 2004, 2003a, b, c, 2000a, b, 1995), who comes from an applied CA perspective, the additional contextual information I bring to my work follows the research ideology of discourse analyst Heidi Hamilton who argues

that it is “...legitimate (if not imperative) for the analyst to be in the role of participant-observer” (Hamilton 1999, p. 169.). Similar to Goodwin’s and to my own work, Hamilton based a great deal of her research on interactions with one person, Elsie, a friend she grew very close to during her years of coping with Alzheimer’s. Hamilton claims that in order to determine what is happening in their interactions, the analyst must “rely on an insider’s knowledge of what has been shared over time” (Hamilton, 1999, p. 169).

In my own analysis, readers may find interpretations of data that rely on my insider’s knowledge of my family workings. I believe that it is impossible to separate myself from this knowledge and that bringing this to bear on my analysis actually enriches rather than detracts from the interpretations. While I model the techniques of Goodwin, using applied CA to study the local agenda of making meaning with my father as I perform microanalysis of our actions as they unfold, I also draw on the theoretical position of discourse analysts toward context. Rather than pursuing this research with a goal of bringing new categories of identified actions back to the main canon of pure CA literature, my purpose is to bring knowledge about conversations with family members with PD to bear on therapeutic applications. I adopt Hamilton’s (1999) view that,

The key to a personal approach is that it does not ‘stand outside,’ taking the position of a detached and unaffected observer. At its core, it works interpretively and empathically, going far beyond the measurement of indices or the codification of behavior. In all of this the researcher takes a personal risk...It is on the ground of our own experience in a relationship that we can gain some inkling of what is happening to another (pp. 169-170).

While research on communication disorders such as Hamilton's (above) that stems from Discourse Analytic approaches validates the subjective, insider's account of actions, it does not provide enough of the detailed mechanisms of how participants co-construct meaning on a moment-by-moment basis. By drawing on different aspects of these methodologies, I am able to use the detailed turn-by-turn categories of action already identified by CA researchers while also bringing context that is exogenous to the interaction at hand to bear on the present analysis (a DA approach). This hybrid analytic approach may help to demonstrate that applied CA and DA are more compatible and mutually informative than they are distinct as they are both used in the pursuit of examining action in specific social situations. Rather than contributing to literature that argues the differences between CA and DA I hope to add my new perspective which posits that they are complementary.

Description of Analysis

As a first layer of analysis, I watched the video footage and took notes on interesting occurrences in our conversations as I imported each videotape into Macintosh's I-Movie program. I have the data stored on an external hard drive dedicated exclusively to this project. While many of the videotaped conversations show Dad participating minimally, there are several where he is fully engaged in conversation during the entire duration of the tape. As a second layer of analysis, I decided to transcribe an entire tape that records Dad talking for the full hour. This process helped me to look closely at the strategies we were using when Dad was deeply involved in conversations.

Through the note-taking and transcribing processes, I began to see certain interactional patterns. As my original research question is, "How does my family come to communicate with a member whose speech is severely impaired by Parkinson's disease?" I began to categorize the

interactions based on the communication strategies we use. Using Goodwin's comprehensive literature on conversations with an aphasic man as a guide, I begin to look for patterns that were similar to those he identified in my own data set. As we are not able to rely entirely on Dad's phonological stream for complete understanding, I noticed that throughout the data set, our family uses three other main strategies:

1. Indexing objects or events in the Environment through pointing or other bodily gestures (Environmental Indexing)
2. Focusing on narrowing down the possibilities of meaning in Dad's phonological stream over multi-party turns (Scaffolding)
3. Drawing on our lifetime of family discourse to interpret meaning (Life Narrative).

The three findings chapters (5, 6, & 7) are organized according to these three main strategies. After defining these categories broadly, I watched all the video footage again. While watching, I coded my previous notes for each of the strategies. During this coding process I realized that each of the categories of conversational action could be further specified. For example, I noted that the ways in which Dad indexes objects in the environment take on different forms and have different functions. I created more specific categories of action for each of the three overarching groups of strategies and then coded the notes (see Appendix C) for each of these subgroups.

Reading through the coded data allowed me to find the best representative examples of each of the subcategories. Once I identified the best examples of each interactional strategy I again re-watched and transcribed these representative encounters. In order to demonstrate how bodily movements are co-deployed in real-time along alongside phonological streams of sound, the transcriptions are close, displaying the timing of actions with the timing of sounds. I

transcribed changes in intonation, pauses in speech, volume changes, and other physical actions as they are relevant to the co-construction of meaning in each interaction (for transcription conventions, see Appendix B). I used two different approaches to representing Dad's speech sounds in a written form. In most situations, I looked to subsequent turns to determine how to transcribe Dad's utterances. That is, I used the response of Dad's interlocutors to his utterances as a reference for establishing what a particular interlocutor understood at the time the conversation took place. The interpretation of what an interlocutor understood at the time is likely more accurate in the examples from the scaffolding chapter (Chapter 6), where interlocutors are seen to repeat parts of Dad's utterances as a way of negotiating the missing meaning.

It is more difficult to know what an interlocutor understood during an interaction in cases where they do not make overt references to Dad's speech. In some cases, I was still able to gain an understanding of what the interlocutor heard at the time by watching our ensuing actions. If we are seen to follow Dad's verbal instructions for example, I transcribed his sounds based on what we must have known in order to have done those particular actions.

I encountered certain instances when it was very difficult to tell exactly which of Dad's different semiotic strategies allowed us to understand him. Sometimes, it appears that it could be a combination of where we are in space, understanding a small amount of his phonological stream, and perhaps also a facial expression or other gesture. In these instances, I tried to watch the interactions in slow motion to see if I could find indications of when, during the co-deployment of multiple actions, Dad's interlocutors understood him. I then transcribed based on my most educated interpretation of what was likely to have been understood. These

transcriptions will serve as a primary way for readers to have access to the actions of participants in this study.

Checking the Narratives and the Analyses with the Participants

As both a courtesy to my participants and a way for me to check the accuracy of my family narratives and my interpretation of the transcripts, I asked my mother to read Chapters 1, 3, 5, 6, and 7 (the two chapters I did not ask her to read are the Literature Review and the Theory & Methods chapters). She and I also read most of Chapter 1 outloud to my father, but in the interest of time, we did not continue to read the entire dissertation outloud to him.⁵ In reading the Prologue to my father, I was checking to make sure he did not find my representations of his physical impediments or my characterizations of his speech to be offensive or embarrassing. While I intended the Prologue to be humorous at the end, Dad started to laugh very early into my description of his present eating habits. The line, “He starts with ambitious amounts piled on his spoon to compensate for the food he will lose to the table, his lap, or his chest” engendered fits of laughter in my father, which I take to mean that my representation of Dad’s eating strategy rang true for him. While I was reading, I stopped frequently to ask if what I had written was ok or if he wanted me to change anything. Dad did laugh again heartily at the end of the Prologue and said he thought the section was “very good.” My mother also listened to my reading of the Prologue and thought I had presented an accurate portrayal of a typical mealtime conversation at our home.

Upon re-reading Chapter 1 on her own time, Mom did take issue with certain fictionalized representations of the actions of people at Dad’s senior day care center. Although she acknowledges this narrative was understood to be somewhat fictionalized, she asked me to

⁵ I do have plans to read the chapters to Dad during future visits home, as he is still quite interested in knowing the details of how the project turned out.

soften my representation of the wheelchair salesperson, as this dissertation would be published. Mom also had very significant contributions and suggestions to make to my family narratives in Chapter 3. She pointed out for example, that the sound sequence I have recorded for Harold's "tractor" denotes a very specific tractor: Grandpa's John Deere. He apparently had ways to distinguish between many different tractors on the farm, but by the time I came to know Harold, there was no longer a working farm, nor any tractors to point to. Also, my mother pointed out to me that Harold did actually work on the farm as a farmhand, right alongside grandpa and the hired help. This information is entirely new to me and has a profound affect on my perceptions of Harold. During my childhood with him, Harold would still hang out with and feed the animals some, but he rarely left the house. Inside, Harold and very rarely got up out of his armchair unless it was to move to the sofa. Over the years that I knew him, his leg muscles became so atrophied from lack of use that he couldn't walk without a walker. According to my mother, all the bad temper problems Harold exhibited were a result of his staying indoors, unoccupied when Grandpa sold off the farm equipment and retired.

My mother also had important corrections to make to my narrative entitled *Early Family History*. It seems that over the years, I have mixed several family stories and confused timelines in my head. My mother helped me to disentangle the stories and straighten out the dates.

Finally, my mother corrected about a dozen grammar or spelling mistakes in my text, including problems that showed up in the Appendices. I mention this only as a way of underscoring how thoroughly she read the text. This indicates that as she did not make any content or information corrections to the other sections of the dissertation, it is because she agrees with the information rather than because she did not read it carefully. The text of this dissertation only displays corrected and edited versions of narratives. In the conclusions chapter

(Chapter 8), I give additional information about Mom's general reaction to reading the dissertation.

Conclusion

In applying the theoretical framework and methodological approach to my data, I have outlined in this chapter, I was able to categorize my findings into three main strategies (Environmental Indexing, Scaffolding, and Life Narrative). These will each be discussed in the following three chapters (5, 6, and 7). Readers will be able to gain insight into how these strategies are used by my family members to co-construct meaning by reading both the narratives and the transcripts that follow in the coming chapters.

CHAPTER 5: FINDINGS A, ENVIRONMENTAL INDEXING

Introduction and Organization

In this chapter, I examine how my family members (my father, my mother, my brother, my brother's girlfriend, my husband, and I) use multiple semiotic means within a semiotically rich environment to both co-construct meaning and to construct my father as a competent interactant. Throughout, I maintain the assumption that sophisticated and complex meanings can indeed be conveyed through gesture. Here I start with a reiteration of the argument presented in Chapter 4 in regards to the need to view gestural forms of communication as equally as powerful as syntax. Next I give a basic introduction to how the physical environment is an integral part to meaning making. I then move directly onto my findings. Finally, I provide a summary of the findings and note their significance for this study.

Syntax and Gesture

Many language theorists posit that the “duality of patterning,” our ability to combine *meaningless* units of sound into *meaningful* units of sound, marks the transition to communication that is decidedly human (Studdert-Kennedy, 2000, p. 152). In this view, the syntactical ordering of sound units that occurs in our brains provides us with an “unbounded lexicon” we can then use to talk about “...a potential infinity of relations...” about any object, event, person, or abstract idea that is not co-present with the interlocutors, (p. 152).

An underlying assumption to the thesis that the duality of patterning alone affords us the unique ability to discuss abstract thoughts or concepts is that the meaning-making through gestural communication systems does *not* have this potential. Gesture is relegated to a

subordinate category of action that has no greater power than to directly index an opaque referent (e.g. pointing) or to serve as supplementary to the primary syntactic generator of meaning. Critiquing such narrow interpretations of gesture, Finnegan notes, “the verbal” is implicitly the norm while ‘non-verbal modes’ can too easily be pictured as merely secondary adjuncts of speech” (Finnegan, 2002, p.7). This is the point of view I outlined fully in chapter 4 in the section entitled, *Theoretical Framework*.

In contrast to the view that syntactical orderings of units of sound are the only means for conveying complicated meaning is research in linguistic anthropology, semiotics and sociolinguistics that suggests that speech is only one of many semiotic modalities that may or may not be co-deployed or overlapping. Meaning, for many researchers in this tradition, is co-constructed during interactions with others while these others are also created in the process:

As a process of the organism, [speech] is not isolated from our gestures, our facial expressions, the rhythm of our movements, the darting of our glances, the whole ‘dance’ of material meaning-making (a dance that always assumes a partner, that always helps to create one) (Lemke, 1995, p. 8).

This “dance” of creating meaning that Lemke refers to takes place in a physical environment that has also been constructed by our interactions within it. Meaning in conversation is often interpretable because our environment is also semiotically rich.

The Semiotically Rich Environment

The physical space in which semiotic actions are deployed and interpreted serves as a contextual background that constrains potential meanings. As producers of meaning, there are many ways in which we draw on our immediate physical environment to help specify our intended meanings. For example, we can point to objects or areas within our physical space, or

we can direct others' attention through a simple glance or an extended gaze in a particular direction. Even the orientation of our bodies within certain physical or social contexts can be meaningful. We can co-deploy physical semiotic resources alongside phonological utterances or we can use these resources on their own to create meaning. All of these semiotic deployments necessarily need what Lemke (1995) calls "a partner" in order for them to be meaningful at all; meaning can only be co-constructed if a conversation partner is able to see and interpret gestures as meaningful. I now turn to my findings section for this chapter to illustrate the multiple ways in which our interactions rely on a semiotically rich environment.

Findings

In this chapter, I focus on the analysis of communicative interaction that relies on the orientations of our human bodies toward other social and physical objects and spaces. The four categories of bodily action I examine are coded as:

1. Environmental Indexing 1 (EI-1), where my family co-constructs meaning using both my father's physical movements and his phonological utterances;
2. Environmental Indexing 2 (EI-2), where we co-construct meaning by relying on my father's actions *alone*;
3. Environmental Indexing 3 (EI -3), where we co-construct meaning by allowing my father to use our bodies to have vicarious interactions with the surrounds; and
4. Environmental Indexing 4 (EI-4), where we co-construct meaning with my father by interpreting his gestures as capable of describing objects that are not co-present.

In the pages that follow, I detail each of these categories of semiotic action and provide analyses of examples.

Environmental Indexing -1 (EI-1)

During the process of coding my data, I found that the first category of action (EI-1) is the most common, with fifty-one occurrences over the twenty-three hour data set. This preponderance of EI-1 demonstrates how important it is to be able to use gesture alongside a phonological stream of sound in order to make meaning. In these cases, it is admittedly difficult to know to what degree our eventual intersubjectively created meaning relied on physical contributions versus speech. Dad's utterances certainly do not sound like those that would come from an interlocutor unaffected by PD. While we can clearly see that his actions are directing our attention and making relevant particular objects or spaces, it is not always clear how much of our understanding relies on the various semiotic modalities that are co-deployed.

Throughout the data set, we co-construct meaning from unique blends of semiotic contributions. Dad often uses his body to help us understand which object he needs or what activity he would like us to do. Allow me to give brief examples before orienting to a detailed analysis of a transcript of a representative video clip. For example, Dad points to certain CDs or records that he wants me to either get and give to him or put somewhere, (see Appendix C, 4.16.06B; 2:30, 10.12.06A, 33:20, 11.08.06B, 00:00-10:40). In directing us to do an activity such as working to cover up the pool for the winter, Dad points to particular areas where he would like the screened patio repaired, (10:30:05 B; 04:50, Appendix C). As he is in a wheelchair, his pointing in this scenario results in my wheeling him closer to the area he is pointing to in order to further our discussion. Although Dad is doing the pointing movements, he is only able to achieve his intended meanings because we coordinate our own gazes to look where he is pointing or

because we move his body or our own bodies to orient to his indexes. In this way, we are all working in concert to co-construct meaning.

In many cases, it is clear that we are following the focus of Dad's eyes to supplement our understanding of his phonological utterances. I follow the direction of his head, neck, and eyes as he is leaning forward in his wheelchair and looking at both his front wheel and the brake (3.13.07B; 03:23, Appendix C). In this situation, I use the orientation of his gaze in conjunction with his utterance (from which I seem only able to recover the word, "move") to eventually figure out that he needs me to undo the brake and move him. Following Dad's gaze seems to be a particularly useful means of semiosis during times when he is experiencing severe bouts of speech impairments. On 3.13.07 B (Appendix C), Dad is having a particularly bad day, where he is mostly frozen and his medicine does not seem to have kicked in yet. At 20:28 (Appendix C), I consider where Dad is looking in order to understand that he wants me to start sorting through a box of cassettes. We see this worsened state again on 4.08.07A (Appendix C), when Dad is in a desperate physical state yet insisting on fixing his wheelchair on his own. Here (4.08.07A, 7:40, Appendix C), as Dad is on his knees, facing a chair, with his hands gripping the arms of the chair firmly and his eyes staring intently at the seat of the chair, he says nothing more than, "up," from which I am able to understand that he needs my assistance in helping him get up from the ground where he has been working and into the chair. Dad's utterance here would likely be uninterpretable if Dad's interlocutor chose to turn away from him rather than trying to find clues in the surrounds to pin Dad's sounds to.

Throughout the data set in general, I have found that when we are able to use Dad's body movements as an aid in our meaning negotiations, we use less repeats, clarification requests, comprehension checks, or scaffolding. This in itself may underscore the importance of gesture in

communicative interaction. We do not seem to need as much assistance when we can see directly what Dad's intentions are based on the ways he activates objects in his environment.

As I noted above, there are many instances of EI-1 in this data set. I have selected one representative excerpt to offer as an example. In the following close transcription of an interaction during dinner, we can see in great detail how Charles and I orient to Dad's pointing and gaze toward objects in the environment as ways of co-constructing meaning.



Figure 4. We coordinate the movement of our bodies

Dad Requests Wine (2.11.06; 01:20 - 01:42, Appendix C)

D=Dad; M=Mom; A=Amy; C=Charles

1 D: erataldeh wine you got?

2 (looking directly at my wine glass)

3 M: You drank it

4 A: A:hh I can open another one this is mine you want more?

5 D: [yehh]

Athens Discourse Inquiry Group (ADIG), a graduate level qualitative research class, a professional conference, a job-talk, and individual friends who are not graduate students of any kind. On several occasions (when playing the data at the conference, the job-talk, and to individual friends), I played only the sound without allowing the audience to see any visual aspects. In all cases, the audience asked me to play the footage again so that they could understand my father's speech. After each time I played the data, I asked the audience if they understood everything he said. While there were always somewhat varied reactions throughout the audiences, I do not recall anyone ever claiming to have understood him based on only the aural semiotic channel. Although I never had the audiences write down what they understood (or did not understand), my general impression after each playing was that the listeners were having difficulty understanding what was happening without the spatial and visual contexts. In other words, they were not able to understand Dad's meaning based solely on his phonological stream.

This information is relevant to both my transcription and my analysis because it serves as an additional layer of evidence that Dad's gestures, body orientations, and gaze are instrumental in filling in meaning when his utterances are independently undecipherable. Dad's utterances in this excerpt are transcribed as they sound to me when I watch the video, as a way of highlighting the weaknesses in his phonological stream that are likely supplemented by his important body movements.

As we see in line 1, the sounds in the first part of his utterance are not readily parsible into words in English. Yet, in line 2, we see that Dad is looking directly at my wine glass. His gaze, in conjunction with some understandable sounds allow both mom and me to understand what he is asking without having to use clarification requests. In line 6, Dad momentarily glances over to a wine bottle on the counter and then looks back at me. Although his glance is

relatively quick, it is long enough for Charles to see what Dad is looking at and then look at the same bottle himself (line 8). Here, Dad's simple glance at the bottle has served to direct Charles' attention to Dad's object of interest. It is possible that the members of my family have a heightened sensitivity to attending very closely to Dad's gestures. Also, Dad may be able to use gaze more concertedly in order to compensate for his loss of ability to make distinguishable words.

Dad fixes his gaze on the wine bottle for a more extended period of time (line 10) as he seems to be trying to verify that there really is no wine left in the already opened bottle. Even though Charles has followed Dad's gaze over to the bottle of interest, I have not demonstrably done so at this point. In line 13, Dad explicitly points to the bottle while continuing to look at it as though by pointing while asking if there's any wine in there he can be sure that we are all orienting to the correct bottle. Indeed, after he points I do directly follow his pointing and Charles also again orients directly to the bottle with his gaze (lines 14 and 16). In line 17, Dad then returns his gaze to my face as though he is sure we are all on the same page now and he simply needs to finish the conversation. In line 23, Dad nods his head along with his quiet "yes," to indicate that he is finished with the discussion of wine.

During this entire interaction, the respective placements in physical space of my wine glass, the empty bottle, and the three interlocutors are instrumental in our meaning negotiation. We are able to recover his referents in our environment by following both his gaze and his explicit pointing. This is a multi-sided negotiation of meaning as Dad seems to need confirmation that we are all looking at the correct object. He receives this confirmation after he directly points to the wine bottle, compelling us to demonstrably look at the bottle.

Clues that are interpretable from Dad's phonological stream ("wine you got?" line 1, "ehdeh in there," line 11, and "yes," line 22) all work together with the co-deployed movement to create meaning. While it is not possible to determine exactly what we understood at the time from each of the different semiotic modalities, it is clear that they all function as an ensemble of communicative resources. In the next section, I explore how my family uses the process of Environmental Indexing to co-construct meaning without contributions from Dad's phonological stream.

Environmental Indexing – 2 (EI-2)

Throughout this data set, there are several instances when our family interprets meaning from my Dad's gestures alone. In this second category of action where Dad indexes himself in relation to his physical surrounds (EI-2), we often respond to Dad's actions in words even though he has made no attempt at words himself. Within this category of meaning creation, there are further distinctions based on whether or not Dad actually intends to convey meaning or is simply going about his business while his interlocutors choose to find meaning in his actions. Often, it is not even clear whether or not Dad means for us to take up his action as meaningful.

There are several situations in the data where it is clear that Dad intends for us to find meaning in his body movements. For example, on 4.16.06 B, (Appendix C) Dad and I have been working together to put away his records. Once we have finished this task (at 4:20, Appendix C), Dad points directly out in front of him, toward the computer indicating that he wants me to take him over to the computer. I clarify that this is the case and he approves of my interpretation. On 11.08.06 at 3:40 (Appendix C), at the dinner table, Dad moves his hand from the sauce on the table to his plate. He does this twice while looking at me and although he makes no speech sounds at all, I know that he wants me to pour some of the sauce onto his food. While I do not

clarify my interpretation through words, we can safely assume that I was correct based on the fact that Dad does not stop me from pouring the sauce, but instead looks satisfied after I've finished.

In other instances, where my family interprets meaning from Dad's actions only, it is less clear that he intended for us to do or say anything in response to his body positioning. We even sometimes make meaning out of a lack of movement and then start a conversation based on his inability to do or say something. For example, on 6.09.07 and 6.10.07 (Appendix C), Dad is having particularly difficult days. His medicines seem not to be working for him and he has exhausted himself doing strenuous activities the previous day. At the beginning of the tape on 6.09.07, (Appendix C) Dad looks desperately stuck, leaning forward in his chair, seemingly against his will. I interpret these body positions as meaningful and at 01:08, I ask him if he is ok. He simply nods his head slightly in response. The state and positioning of Dad's body also seems to provide a connotation to my mom who, directly upon coming to the dinner table assesses his situation and immediately begins to feed him. In general, she waits to see if he is able to successfully feed himself or waits until he asks for help. In this case, however, she sees the condition of his body and perhaps the look on his face and interprets them to mean that he is not in any state to feed himself.

In the excerpt below, Dad does make an active movement that Mom and I both take to be meaningful. We are all eating dinner at the table, yet Dad stops eating to reach toward his bag that he takes with him every day to his senior day care center. He makes absolutely no sound at all and does not even look at any of us at the table with him before, during, or after the gesture (he is not enlisting our attention as in the previous example). Nonetheless, Mom responds verbally to his body movement as though it were an utterance. Although Dad does not verbally

initiate a conversation, it does appear that he was interested in discussing what he is looking for in his bag. If Mom had not decided to read Dad's simple gesture as meaningful, no meaning would have been co-constructed. Dad may instead have continued to be frustrated with not finding his objects of interest rather than having the opportunity to appeal to his family members for help. Before continuing with a more detailed analysis of this interaction, allow me to give the necessary background context.

On the day this was filmed, Dad had been at his adult day care center all day, where the other clients spent the afternoon hand-making birthday cards for him. When he got home from the center, Dad told my mother about the cards. He was upset because they were very important to him, but when we arrived home, he was unable to find them in his bag. By the time the conversation in this excerpt takes place, my mother had already asked me about these missing cards. As I had picked Dad up from the center, she wondered if I had seen the cards anywhere as we were leaving. Mom and I both know how preoccupied (perhaps somewhat obsessed) Dad is with finding these cards

Looking For the Cards (2.11.06; 10:35-10:45, Appendix C)

D=Dad; M=Mom; A=Amy

1 D: (*reaching for his bag*)

2 M: We'll look for you cards tomorrow.

3 (.....*monotone voice*.....)

4 A: I didn't see anything on the table when I picked you up except your cd. (.) which I

5 did pick up=

6 D: °mm°

As mom responds to Dad's movement in line 2 saying, "We'll look for your cards tomorrow," she assigns meaning to his reaching motion and initiates a conversation that Dad may not have intended to have. The monotone voice she displays may be a result of her exhaustion with the topic. They have both checked all his belongings at this point and occurrences when Dad forgets or misplaces things and needs Mom's assistance as he searches obsessively for them are becoming increasingly frequent. It is quite possible that Mom is trying to pre-empt yet another conversation or search during the middle of his birthday dinner by interpreting his action as meaningful before he actually has the chance to start talking about it again.

In line 4, I take up the topic of conversation as though I know I will be held accountable for the missing cards. Although Mom and I have talked in private about his missing cards at this point, I have not yet told Dad directly that I have also been active in finding them. In line 6, Dad shows that he understands that I have looked for them (perhaps my exculpation) with a simple "mm." As we will see in the next chapter (Chapter 6), we work over several turns to finish this conversation, where Dad contributes, "There were enough people gathered around that table to ensure that I took everything." He concludes the topic with his own assessment of how he could not possibly have left the cards on the table at the center.

Interestingly, after we have finished eating but Charles, Dad, and I are still seated at the table, Dad again reaches for his bag, picks it up, opens it, and looks inside (see Figure 5), (2.11.06, 25:20, Appendix C). It would seem that Dad temporarily accepted Mom's offer to look for the cards the next day, but as soon as dinner was finished he felt compelled to look for them himself anyway. At 25:58 (Appendix C), as Dad goes through all the belongings that he took with him to the center that day I say, "Dad are you looking for those cards I think Mom already

went through the whole thing.” Dad does not observably respond to my commentary but at 26:18 (Appendix C), he puts his bags down and resigns himself to just sitting at the table, waiting for his dessert to be delivered.

During these interactions about Dad’s missing birthday cards, Mom and I have both started conversations based on Dad’s activity alone. We find meaning in his actions, treating his search as though it were an utterance expressing concern for his cards. Dad never enlists our help or even our attention, yet we both read his body movement as needing a verbal response.



Figure 5. Dad looks for his missing birthday cards

Environmental Indexing – 3 (EI-3)

The third category where body movements and orientation toward the environment become integral to our meaning making (EI-3), occurs when Dad uses his interlocutors’ bodies as the relevant site for semiosis. This situation generally arises as Dad is directing those around him to do things for him yet instead of pointing or making other explicit gestures himself, he uses the body positioning of his interlocutors toward objects and tasks in conjunction with verbal

commands to coordinate action. We can liken this pattern to the relationship between a puppet master and his puppet, where the master is able to have vicarious experiences by moving his doll. Dad does not point directly to objects (as in the EI-1 case), but rather uses our established relationship to an object or group of objects to move our bodies. In each of the situations coded in the data set, Dad's interlocutors are already touching object that Dad wishes for them to manipulate in specific ways. Rather than telling us to do a task and then allowing us to sort out exactly how to go about accomplishing his request, Dad uses the way in which we are already connected to objects in space to manipulate our actions on a fine-grained level. In this way, he is able to get us to accomplish tasks that he lacks the manual dexterity to perform. We are also able to figure out his intended meaning through our established relationship to the objects. Importantly, we are directed to do them in exactly the way he wants them done, allowing him to experience the task for himself through our bodies. Throughout the examples of EI-3 that follow, it is important to note that Dad's interlocutors display the "cooperative attitude" Sabat (1999, p. 116) describes in regards to people who cooperate with the speech of individuals with Alzheimer's. The participants here are able to co-construct meaning because we make our bodies available for his semiotic means.

In the data, I have found multiple examples of Dad playing puppet master. On 4.06.06 (B), from 00:14 – 1:20 (see Appendix C), I am attempting to help him put away his records, yet I note that I am having difficulty understanding his phonological stream. Dad starts out by pointing explicitly to a group of records within which I should order the record in my hand (an example of EI-1), yet once I go ahead and place my hands on the group of records, he directs me more specifically to "go left," further narrowing the possible places where I could put the record. As I then page my way through each record on the shelf within this narrowed area, he stops me

at a particular spot and says, “There! There!” directing me to the exact location of the record. Similarly, a few minutes later in our interaction at 13:00, (4.06.06 b, Appendix C), I am putting a record on the gramophone for my father. There is a specific movement of a Shostakovich symphony that Dad wants to hear, yet I am experiencing difficulty with dropping the stylus directly on his desired track. Each time I drop the stylus to the record, Dad rejects my action and then looking directly at the whole record, tells me I need to move 2 tracks to the left still. Eventually, I manage to find the right track. He is not able to use any specific pointing gesture, but rather manipulates my hand through his verbal utterance and the current relationship of my hand to the stylus and the tracks on the record.

On 7.26.06 (see Appendix C), Dad is directing me to look up certain new recordings of classical music online and to inquire into their purchase through Amazon.com. During the entire tape, we are fully engaged in this process. Dad is sitting to my left in his wheelchair, holding the most recent issue of the *Gramophone* magazine in his lap. He has paged through the magazine for several days leading up to this interaction and has cultivated an interest in many of the new artists’ recordings and conducting of familiar works. What is most fascinating about this hour of interaction is perhaps the simple fact that Dad could have very easily just laid the magazine down and pointed to particular names for me to type into the search engines for him. This interaction would then have been coded as a case of EI-1. Instead, Dad chooses to keep the magazine in his own possession during the entire interaction, reading out names to me that I consider to be relatively obscure and foreign.

As we negotiate our way through this process, my hands are poised on the keyboard but I am not given the privilege of knowing how to direct my fingers to the necessary keys until Dad tells me specifically how to operate. From 18:20 – 44:00 (7.26.06, Appendix C), Dad attempts to

pronounce five names that I do not know how to type at first (18:20: “Neilsen”; 23:01: “Beecham”; 28:18: “Barenboim”; 36:00: “Herz”; 43:30: “Byondi”). In each of the cases, I either ask Dad to spell the name for me at the time of his request or I go ahead and type it incorrectly and wait for Dad to look at my spelling on the computer screen and then verbally correct it. By only reading out one name at a time and by spelling the names for me rather than simply pointing to them in a magazine, Dad controls my access to information and thereby also controls my ability to perform the task in any way other than how he wants it done. Using the relationship of my body to the computer and keyboard, it is as though he is typing in the names himself, using my body as an instrument for his own actions. The meanings that are created here are a result of the process of co-construction as we let Dad direct our bodies rather than trying to direct our bodies ourselves. In this conversation for example, I could have grabbed the magazine from Dad and read the names rather than letting him read them and direct my fingers on the keyboard. In the transcript that follows, we see how Dad uses the relationship between Charles’ body and a group of antique lamps in order to coordinate the activities he would like to get done.

Picking out a Lamp (10.30.05 B; 45:25 – 46:53, Appendix C)

- 1 C: (*wheeling Dad away from the lamps Dad still wants to talk about*)
- 2 D: eh na dha ne wul suh swu no ore na white with the [shade eh globe eh te top of ne
- 3 next to a toh] (*pointing to the lamps that are now almost behind him as Charles*
- 4 *turns his wheelchair around*)
- 5 C: (*[placing his hand on the lamp*
- 6 *Dad is directing him to]*
- 7 (*slowly moving his hand to another lamp, then pointing with his finger; then*
- 8 *touching the lamp*)

9 D: there. (1.0) by y by your hand the globe

10 C: this one

11 *(moving both his hands to the lamp he has just been pointing to, but appearing to*

12 *go for the lamp in front of it)*

13 D: no eh.

14 C: *(retracting his hands temporarily in response to the “no”)*

15 D: that one yeah that one

16 C: *(goes to move the lamp that is in front of the lamp he is concerned with)*

17 D: no no no no. the one behind it

18 C: *(takes his hands off the lamp he was moving)*

19 this one.

20 *(moving his hands past the globe lamp to the one behind it, then explicitly pointing*

21 *to the lamp in the back)*

22 D: tha two behind it

23 C: *(goes to pick up a lamp in front of and to the right of the one in the back)*

24 Agghhhhh

25 *(sighing as the lamp base he picks up separates from the top, then kneeling to*

26 *to screw the lamp back together)*

27 D: Egh eh do the other one

28 C: this one?

29 *(pointing to another lamp that is similar to and right next to the one he has*

30 *been working on)*

31 D: Yeah. and the globe on top of tha le b er ater uh tp rou the wah

32 C: How many lamps are we taking?

33 D: No:: no no. ehsis fer Andrew

34 *(shaking his head)*

35 C: What's that? (2.0) Ah. Ok.

36 D: that gohber there

37 *(pointing to a lamp)*

38 C: *(reaching his arm to where Dad is pointing)*

39 A: the [back one?

40 D: [be hin behind it

41 C: this one (2.0) with the bi[g

42 *(standing up to gain better access to the lamp)*

43 D: [no why weh jump two?

44 C: *(moves his hand to a lamp closer to*

45 *himself – the lamp with the globe shade on it)*

46 D: behind that one yes

45 C: yes this one.

46 D: the globe.bir

47 C: Um hm.

(nodding his head in understanding)



Figure 6. Charles points to a lamp as Dad directs him

As a hobby and a way of making a little extra money, Dad used to deal antique lamps when we lived in New York. After moving to South Carolina, Dad stopped selling the lamps but retained plenty of his stock for house decorations. Dad decided he would like to give Charles and me a couple lamps for our new house and on the day this tape was filmed, we spent several hours trying to assemble lamps to Dad's specifications. As he lacks the dexterity in his fingers to manipulate these fragile items on his own, he has spent much of the day directing us through the process of lamp assembly.

Just before the occurrences recorded in the transcript above, Charles and I have drawn the conclusion that we are finished with the project and should move Dad out into the living room. As Charles is wheeling Dad away, however, Dad tries to point over his shoulder to a group of lamps that are behind him. Dad's speech is very difficult to understand, but Charles is able to

understand that Dad wants him to attend to a particular lamp with a globe on top (lines 2 and 3). The actions that ensue define a new category of Environmental Index where a speaker directs his interlocutor's body through space as a sort of puppet master. Throughout this entire interaction, instead of pointing himself to objects of interest himself, Dad uses vocal commands to move Charles' body through space. This situation is different from instances when Dad simply commands us to do a chore, as Charles' body is commanded at a very fine scale of movement. Allow me to orient to the data to demonstrate.

After pointing out the group of lamps he is interested through his own explicit arm movements and hand gesture, Dad then begins to use Charles' body vicariously to point for him. The positioning of Dad's wheelchair in relation to the group of lamps is essential for understanding why vicarious pointing is necessary for Dad (see Figure 6). Charles walks over to the lamps and as he moves his hand toward a specific lamp, Dad stops his movement by saying, "there" (line 9). The interaction then becomes an extraordinarily complicated negotiation of Dad's meaning. For the convenience of readers, I include a portion of the transcript I am referring to from above here.

D=Dad; C=Charles

9 D: there. (1.0) by y by your hand the globe

10 C: this one

11 *(moving both his hands to the lamp he has just been pointing to, but appearing to*

12 *go for the lamp in front of it)*

13 D: no eh.

14 C: *(retracting his hands temporarily in response to the "no")*

When Charles requests clarification of exactly which lamp Dad is interested in, he moves both of his hands to the globe lamp. Importantly, on his way to the globe lamp, he passes by another lamp in front of it, while saying, “this one” (line 10) which seems to make Dad think he is referring to the lamp in front rather than the globe-shaded lamp. As Dad corrects him saying, “no” (line 13), Charles momentarily retracts his hand from the globe lamp where his hands are located at that time. This is the basis of a misunderstanding that continues to need complex negotiating of meaning throughout the next several turns. Watching the video dozens of times with Charles has allowed me to re-construct the details of how he eventually came to an understanding with Dad.

As Charles is in the process of retracting his hands, it appears Dad then “catches up” with where Charles’ hands *were* (on the globe lamp) and says, “that one, yeah that one” (line 15). Here again I include part of the full transcript entitled, *Picking Out a Lamp* displayed earlier in this chapter to ease reading.

15 D: that one yeah that one

16 C: (*goes to move the lamp that is in front of the lamp he is concerned with*)

17 D: no no no no. the one behind it

18 C: (*takes his hands off the lamp he was moving*)

19 this one.

20 (*moving his hands past the globe lamp to the one behind it, then explicitly pointing*

21 *to the lamp in the back*)

At this moment in time, Charles and Dad have converged upon Dad’s intended meaning (as evidenced in lines 20 and 21), but as Charles goes to move the lamp out from in front of it to get to the globe lamp, Dad says “no, no, no, no” likely assuming that Charles then thinks the front

lamp (not the globe) is his lamp of interest. When Dad continues his commands for Charles' hands by saying, "the one behind it," Dad's point of origin is the lamp in the front, yet Charles' mental point of origin is still the globe lamp. This mismatch of points of origin leads Charles to move past the globe lamp and go to the lamp behind it, explicitly pointing to this new lamp at the very back (lines 20 and 21; see Figure 7).



Figure 7. Charles points to the lamp in the back

As Charles then changes tack to approach this lamp in the back, he finds he first needs to move other lamps out of the way. Unfortunately, when he goes to move the first of these lamps, the base separates from the center and he sighs as he kneels down to screw them back together. When he finishes, Dad commands him to "do the other one" (line 27). Here, Charles takes "the other one," to be the other similar lamp just next to it that requires screwing back together as

well. It is because Charles' hands are already fixed on a lamp with a particular need that Dad is able to command his hands accurately through his words to the lamp next to it.

It is unclear what Dad is saying in line 31 and Charles' reaction seems too broad for me to know what he heard Dad say in the moment. What is evident, however, is that Dad is again trying to direct Charles to do something that he is confused about. As Dad explicitly directs Charles' next movements, he does make the effort to point himself to a lamp (see lines 36 and 37 below). Charles follows his pointing and reaches to where he sees Dad pointing (line 38).

36 D: that gohber there

37 *(pointing to a lamp)*

38 C: *(reaching his arm to where Dad is pointing)*

39 A: the [back one?

40 D: [be hin behind it

He places his hand on the globe lamp (line 38), yet in watching the video and talking to Charles about the event, it seems Dad cannot tell from his point of view that Charles' hand is on the globe. It looks as though Charles' body and arms are blocking Dad's view entirely, which again causes them to have two different points of origin. These divergent points of origin in turn affect how Charles acts upon Dad's next command. In line 40, Dad again "moves" Charles' hand by directing him to "the one behind it." Unfortunately, the "it" has not been agreed upon and we see Dad's frustration at what he perceives to be Charles' mistake when in line 43, he angrily questions, "Why did you jump two?" This remark serves to move Charles' hand back to the globe lamp that has been the focus of this entire interaction.

41 C: this one (2.0) with the bi[g

42 *(standing up to gain better access to the lamp)*

43 D: [no why weh jump two?

44 C: (*moves his hand to a lamp closer to*

45 *himself – the lamp with the globe shade on it*)

46 D: behind that one yes

45 C: yes this one.

46 D: the globe.bir

47 C: Um hm.

(*nodding his head in understanding*)

Throughout this difficult communication, the physical placement of Charles and Dad's bodies in relation to the lamps is essential. If Charles had placed Dad closer to the group of lamps, Dad could have perhaps pointed with his own arms with more precision. Instead, Dad is about three feet from the lamps and has to use the relationship of Charles' body to objects in order to "point" to what he is interested in. Each time Charles moves his arms and hands through the space where the lamps are gathered, he has to wait for further approval or commands from Dad to tell him where to go next. Rather than devising a set of instructions that rely entirely on verbal descriptions of particular lamps, Dad specifies lamps only as they stand in relation to *his perception* of the current position of Charles' hands. Through this complex negotiation process that takes place over approximately one minute and-a-half, they eventually agree that Charles has found the correct lamp. Rather than immediately and opaquely pointing directly to one referent in the environment, Dad uses Charles' body to differentiate objects in the domain of scrutiny. As Dad's phonological stream and body movements are restricted, the two of them have to work together over multiple turns to co-create his meaning. Even though Dad yells at Charles several times during this interaction, Charles does not stop working with Dad until he is satisfied that

they have agreed upon Dad's meaning. While Dad's tenacity is instrumental here, as he also continues the co-construction, it is Charles' grace and control that are most extraordinary here. In the next section, I examine how we can co-create meaning with Dad by understanding how he makes gestures that refer to objects and concepts that are not co-present.

Environmental Indexing – 4 (EI-4)

In the transcript I have chosen to represent the fourth way in which my family uses our relations to objects in the environment to anchor his difficult phonological utterances, we see how Dad is using his arms to create meaning (see Figure 8).



Figure 8. Dad outlines the bookshelf in the music room

Outlining the Bookshelves (4.08.07; 46:00-46:52, Appendix C)

1 D: enehéf en there

2 A: your what in there?

3 D: eh mookshéf topshelf the buh the bookshelves

4 (*raising his arm and patting down with his hand*__)

5 A: what do you want?

6 D: in ner <ners a record> I muh my il maestro di capella

7 (*_____with his arm still raised_____*)

8 A: dih uh is it sitting out?

9 D: no is its in a book with a brown cover (1.5) li light brown.

Here, Dad is trying to enlist my help to go get a libretto for one of his favorite operas from the music room. In line 4 (and in figure 8 above), we see that Dad raises his arm up directly and then makes a motion with his hand that indicates the presence of a shelf (patting down with his hand) while trying to direct me through his verbal channel to go to top shelf of the set of bookshelves. Instead of questioning his previous utterance, I ask for a repeat of what exactly it is that he wants. Dad continues to frame the outline of the top of the bookshelves with his arms until the end of his turn in line 7.

Here, Dad is using his own body to draw out (or point to) a space that is not in the same room with us. Used in conjunction with the clues from his verbal stream, I am able to understand exactly where he wants me to look when I go in the music room. Goodwin (2006) calls this activity reference to “transposed space.” I simply have to transpose the physical space he has outlined into a different context, a kind of spatial intertextuality (Blommaert, 2005).

Anchoring Meaning Within a Different Activity Frame

To further underscore the importance of indexing events or items in our environmental surrounds as a strategy for co-constructing meaning, I include this final transcript. While Mom is still trying to get information from Dad about how to close the pool for the winter, he hears a bird chirping on the television. As we see in the transcript below, Dad attempts to make a jovial comment about the bird, intending to say, “a bird thinks it’s spring,” yet my mother does not understand his phonological stream.

A Bird Thinks It’s Spring (11.23.06; 33:49 –35:00, Appendix C)

D=Dad; M=Mom, A=Andrew

1 *(A bird chirps [33:49] on the TV while Mom finishes her last utterance to Dad)*

2 D: a bird niks ispring

3 M: what?

4 D: abir niksispre

5 M: what is free?

6 A: *(looks over at Karolyn, placing head in hand)*

7 D: a bird thiks ispring

8 M: the birds think it’s spring?

9 A: that was [on the tv

10 *(mostly to Karolyn, not to Mom)*

11 D: bird thi[ks ispring a bird thiks ispring a bird thinks it’s spring[a bird thinks

12 it’s [spring *(increasing his volume each time he repeats the same utterance)*

13

14 A: [a bird=

15 M: °[I heard you° yo[u're putting breakfast all over the place

16 (grabbing his elbow)

17 A: [he's frustrated

Dad repeats the same utterance three times before Mom understands an approximation of the words he has been saying. Yet, Mom doesn't quite get all the words right. In line 8 she says, "the birds think it's spring," likely referring to anonymous multiple birds outside. Dad, however is referring to a *specific* bird he heard singing on the television.

Although Mom achieves the gist of the words mom is saying, she does not seem to get his intended meaning. Dad, knowing that he was not understood is likely frustrated when he starts yelling a fast string of repeats of the exact same utterance four times with no break. In Goodwin's terms (2000b), this would be understood as an interaction where an interlocutor has given a candidate target, but the target is embedded within the wrong activity frame. Mom cannot understand Dad's real meaning because she is orienting to the activity frame of potential outdoor activities rather than the activity frame established by the borders of the TV.

In line 9, I demonstrate that I have recovered the correct environmental index for Dad's "bird," but I am turned only to my brother's girlfriend Karolyn when I state that the bird was on the TV. I do not seem concerned with interrupting the interaction between Mom and Dad to clarify Dad's referent. This weekend was the first time my brother had brought his girlfriend Karolyn home when Charles and I were also home. It is likely that I felt more of a responsibility to explain the interaction to her than to help my mother who has more experience than I do at figuring out language. As Mom grabs Dad's elbow and speaks back to him in a lowered tone of voice, it appears that she is trying to tame the aggravated level of the conversation in front of her guest. That is, she may not be so concerned with delving into the multiple layers of meaning in

Dad's utterance when she has just been quite overtly yelled at in front of a potential new member to our family. I also choose not to help Dad make his meaning clearer perhaps because I am also embarrassed by the dynamics of their relationship being played out in front of Karolyn. Family members seemed reluctant to pursue Dad's intended meaning perhaps because the strategies we would have had to use to do so may be considered "rude" by an outsider unaccustomed to our family dynamics.

This interaction demonstrates just how difficult it can be for my family to co-construct meaning with my father. In this scenario, Dad's actual sounds are not recoverable at all until his third repeat. Even after he puts all this effort into making a simple comment, once his words are understood, we have still failed to build toward his intended meaning. I am not helping with the co-construction even though I have been able to recover the referent in our physical surrounds. As the chirping bird on the TV was an ephemeral event, Dad cannot direct our attention to the physical space he is referring to through either pointing or gaze. Here, being able to index the correct bird of referent also depends on the timing of an event which becomes increasingly difficult to relate to Dad's utterances the more times he has to repeat. Dad's meaning is not co-constructed, but abandoned. This example portrays a deviant case, yet it allows us to further our understanding about the other examples where we did achieve intersubjectivity. This transcript underscores the importance of negotiation in meaning construction as this scenario would have required even more turns-at-talk in order to narrow down Dad's target by embedding it within the appropriate activity frame. Meaning was not conveyed directly from Dad's mind into Mom's through a perfect transfer process, but was rather a continued and imperfect process of negotiation.

Summary of Findings

In this chapter I have examined four different ways in which my family co-constructs meaning with my father by using body orientations, gaze, and gesture to anchor meanings within the semiotically rich environment. We have seen how my family can use gesture and gaze in conjunction with Dad's phonological stream, how we can use gesture without an accompanying phonological stream, how Dad can direct our bodies as if he is a puppet master, based on our established relations to the environment, and finally how Dad can use gesture to help describe to us an object and space with which we are not co-present. These findings differ somewhat from Goodwin's because his subject was not able to produce a phonological stream of words at all. Dad's interlocutors, on the other hand, can sometimes rely on the co-deployment of words and gesture. Although Goodwin describes how his father directs others actions, he does not examine how a disabled actor can direct actions on such a detailed scale as I have done, where the interlocutors' body becomes an extension of Dad's body. My findings from this chapter add to Goodwin's extensive findings on aphasic speech because the pathology of PD is somewhat different, allowing me to identify additional categories of action. Recognizing these different ways in which my family uses the relationship of our bodies to the environmental surrounds to co-construct meaning emphasizes how our family allows Dad's abilities to factor significantly in our interactions. As we all work together to create meaning, we help construct Dad as competent rather than highlighting his deficits by ignoring his uninterpretable utterances.

CHAPTER 6: FINDINGS B, SCAFFOLDING

Introduction

In the previous chapter I examined how my father uses multiple types of gesture to provide us with an environmental index to recover in our physical surrounds. His gestures may carry meaning when deployed on their own or in conjunction with speech sounds. The timely use of gesture often allows my father's interlocutors to more readily understand vocal utterances that may otherwise be uninterpretable. During my first level of analysis, I noticed when the topic my father is trying to discuss does not lend itself easily to the use of gesture, we use an entirely different strategy to negotiate meaning in the absence of gestural contextual clues.

Conversation Analysis research has generated a tremendous body of work that treats the issue of misunderstandings in talk (Schegloff, Jefferson, & Sacks, 1977; Schegloff, 1979; Fox, Hayashi, & Jespersen, 1996; Egbert, 1997; Drew, 1997; Laasko, 2003; Curl, 2005). Generally, the process through which people identify and attempt to resolve misunderstandings is called repair. Conversation analysts have discovered multiple types of repair that occur under different circumstances and that are conducted by different interlocutors (Schegloff, Sacks, & Jefferson, 1977). The repair mechanisms that come closest to capturing the processes our family uses would be "other-initiated" and "partial repeat." "Other-initiated" repairs occur when a listener initiates a repair of the previous speaker's utterance through multiple different devices, including statements such as "huh?" "what," "you mean X," and so forth (Have, 1999, pp. 116-117). Partial repeats of a speaker's utterance by another interlocutor also give the original speaker the opportunity to reject or rephrase what they have said (Have, 1999).

In the application of these repair categories, when my father utters something undecipherable, his interlocutors would all be the “others” who initiate a repeat by repeating the part of the sentence that we did understand, allowing him to see where he can fill in the rest of the misunderstood part of his utterance. As my father is someone with such severe speech hindrances, it often takes my family several turns to collaboratively figure out what he is saying. A partial repeat of his original utterance is not always sufficient for recovering his meaning. Instead, we tend to embark on a more complex interaction that is not explained fully by a partial repeat. Also, the term “repair” connotes that there is something wrong or broken that requires fixing. This promotes the idea that interlocutors are moving backwards in their conversation to fix a trouble source. What I have noticed in my analyses of my family’s conversations is that we often do not go back and fix a single or even multiple trouble spots. Instead, the process we use may build from new or more creative utterances that are attempts to move on to saying something slightly different rather than fixing a minor miscommunication. I propose that scaffolding thus more accurately portrays this type of interaction in my family.

Several researchers who work on interaction with people with speech disabilities have analyzed the communication breakdowns that occur in conversations with this population of speakers and have come up with their own terms for identifying the actions of non-impaired speakers (Hamilton, 1991; Whitworth et al., 1999; Schegloff, 2003; Goodwin, 2003). Hamilton (1991), for example, identifies a broad category of scoping strategy of the interlocutor called “accommodation.” Whitworth et al (1999) identify the interlocutor’s actions as the “provision of target output,” while Schegloff (2003) says interlocutors are providing “alternate guesses,” and Goodwin (2003) labels the action as the provision of “candidate utterances.”

In my view, “accommodation” is not specific enough of an analytical tool, as it focuses primarily on how the non-impaired speaker changes his or her actions. The term, “provision of target output” connotes that there is only one potentially correct target and presumes that the non-impaired speaker knows what this is. Schegloff’s term “alternate guesses” does show that the non-impaired individual is not the person in control of the knowledge, but the term “guesses” has some connotation that these provisions are random contributions rather than well-formed hypotheses. Goodwin’s term, “candidate utterances” is a term I have adopted throughout this analysis to talk about the contributions of the non-impaired speaker, as this term connotes there are multiple possibilities, but that the impaired speaker retains the right to ratify or reject what has been proposed. Yet, even this term does not provide the means through which to view the turn-by-turn mutual constructions of meaning. In this chapter, I draw on research from child development studies and research in Second Language Acquisition to investigate the co-construction of meaning through impeded or imperfect phonological streams.

Luria and Vygotsky (1980) developed the term “scaffolding” to describe how children rely on input from their elders for socialization into a particular language and culture (Veer & Valsiner, 1991). Now, “The metaphor of scaffolding has been extended in educational psychology to refer to the process by which tutors – parents, caretakers, teachers, or more expert partners – help someone less skilled solve a problem” (Guerrero & Vallamil, 2000, p. 52). Throughout, the literature, there is continued reference to the roles of “expert” and “novice,” categories that are often portrayed as rigid and static.

Research in First and Second Language Acquisition uses the term “scaffolding” to characterize conversational interactions where a more skilled speaker repeats part of her interlocutor’s speech in an effort to elicit more elaborate utterances. Applications of scaffolding

to the area of Second Language Acquisition have the greatest relevance to my own research. When teachers or other native speakers of a language converse with non-native speakers, there are times when the non-native speaker's original attempt at an utterance is not readily understandable (Piper, 2007). The native speaker may use scaffolding as a way to elicit a repetition of the part that has been misunderstood, or a teacher may use scaffolds to elicit more elaborate utterances, thus helping her student to practice his language skills (Freeman & Freeman, 2001).

For this dissertation, I adopt Cazden's definition of scaffolding as "...a temporary framework for construction in progress" (Cazden, 1983, p. 6). Unlike the term "repair" which indicates that there is something wrong that requires going back to fix, "scaffolding" connotes a support structure that is needed to move forward in a conversation. Throughout the analysis, we will see that there are several times when we do not have go back to work on bits of talk. Instead, we just continue working forward with a (perhaps tacit) understanding that we will ultimately arrive at intersubjectivity if we just keep working. In this framework, the person who has greater linguistic skills can help co-construct meaning over long stretches of discourse that cumulatively build on previous utterances. Additionally, scaffolding provides the analytic mechanism to view how a scaffold can be taken up in a next turn in order to continue building meaning.

The data in this chapter is represented in two ways: as a close transcription, and diagrammatically, as a visual representation of the interaction. The transcript is included to allow readers an overview of the turns in the conversation. The graphic visual aid is intended to illustrate scaffolding as a building process. This is also in partial response to Jacoby and Ochs' (1995) highlighting the need to develop new ways to "collect, record, transcribe, analyze, and display naturally occurring data, especially in face-to-face settings" (p. 179). They specifically

call for new ways of transcribing data “as something contingently dynamic and unfolding in interactional time” (p. 179). My diagrams are thus a way of helping readers to view this sequential unfolding and ordering while also perhaps advancing transcription practices.

The original utterance is written across the bottom and forms the base for the rest of our meaning co-construction. The interlocutors’ utterances are aligned above the part of the previous turn upon which they are building. In looking at the time bar at the left of each diagram, readers will note that the sequence of events moves from the bottom up. While this is not the customary direction of reading actions in sequence, the diagrams are intended to give a visual representation of scaffolds as structures of support for future building blocks.

The different colors used in the diagrams have significance as well. Each of the diagrams contains purple, blue, and yellow-coded scaffolds. The last diagram entitled *Last Night* (Figure 12) also includes gray and green color codes. These colors are intended to help readers distinguish between different scaffolds. Readers will note that in two of the diagrams (Figures 11 & 12), multiple lines are included in the same color-coding. This is a way of demonstrating that although the specific words may have changed slightly, these lines that are colored the same still function as the same scaffold. For example, in figure 11, I say “what” in line 8 and “what did you say Dad” in line 12. Even though the exact words have changes somewhat, they function as the same scaffold as they convey very similar meanings without adding any additional information.

Viewing the data in this way helps us to see exactly which parts of an utterance we are working on at a given point in the conversation. For example, we may be only trying to figure out the end of a statement rather than still trying to build support around the entire utterance. Please note that the “co-constructed meaning” at the top of the diagram is not necessarily an utterance that was stated at the conclusion of the conversation. This is intended to demonstrate

the idea or concepts that we are working toward as signified through the talk. Thanks to the many scaffolds that help us to arrive at the ultimate meaning, we often do not need to explicitly summarize the intersubjective meanings we have established. Readers will likely also note that not all the lines of the transcript are included in the diagrams. I have omitted the lines that convey the actions of participants as a way of focusing in on the verbal aspect of our interactions only. Below is the first example of scaffolding.

East of Simpsonville

Just before the above section of conversation, my brother, his girlfriend, and I have all been carrying on a conversation while eating lunch. My father is also sitting at the table, but he is mostly occupied with eating. As we are all musicians, we have been talking about different music groups and issues affecting the music industry. Then, Karolyn and Andrew, who are both experimental biologists, carry on a discussion about hog farms and experimental farms for veterinary pharmaceuticals. We quickly weave in and out of these topics while my father continues to eat. For more details on this tape, see 11.23.06 (Appendix C). The conversation turns back to music and then both Karolyn and Andrew get up to go do their dishes in the kitchen. I am still at the table with Dad when he initiates this conversation. Karolyn and Andrew have started joking on their own in the kitchen about new topics when Dad begins.



Figure 9. Dad appeals to me for help

(11.23.06; 26:16-27:00, Appendix C)

D=Dad A=Amy

1 D: waz uhnum na um pa ish wa uh nu un o sim suh son vi

2 A: what's the name of the Parish of what?

3 D: wuh fel ersi swim sim il

4 A: the one who fell out of the swimsuit?

5 D: the one further East from Simpsonville

6 A: the one further=

7 A: The place further East from Simpsonville.

Co-constructed Meaning	What's the name of the place further east from Simpsonville?
------------------------	--

Time ↑	7 A	the place further east from Simpsonville			
	5 D	east from Simpsonville			
	6 A	the one further=			
	5 D	the	one	further	
	4 A	the	one who	fell out of the	swimsuit?
	3 D		wuh	fel ersi	swim sim il
	2 A	What's the name of	the parish of what?		
	1 D	Waz uhnum na um sonvi	pa ish	wa uh nu un o	sim suh

Figure 10. East of Simpsonville

In this first example where we use scaffolding as the primary strategy to co-construct meaning, Dad is looking directly at me and gives no indication that he is concerned with anything in the environmental surrounds. As I focus on figuring out his meaning by listening to his phonological stream, I use a clarification request as a foundational scaffold asking, “What’s the name of the Parish of what?” (line 2). Here, I am demonstrating what it is that I *did* understand, offering the candidate utterance for either approval or correction while also asking him to repeat the part of his utterance I have not yet understood.

Interestingly, he neither explicitly corrects nor accepts my foundational scaffold. Even though my suggestion “the Parish of what?” is an incorrect suggestion (as we see in line 7), Dad does not repair this part of my offering. Instead, we see in line 3 that the sounds of Dad’s next utterance are similar to those that come at the end of his original utterance in line 1. In line 3,

Dad builds off my foundational scaffold by directly responding to my request for clarification. He focuses on the part of his original utterance of which I demonstrate absolutely no understanding at all. He fills in the largest gap in my understanding first (blue type indicates text that is “filled-in” from the blanks left by scaffolds).

Recognizing this shift to the latter part of the sentence, I in turn build only on Dad’s narrowed focus from line 3. As evidence of my understanding that we are now only working together to make meaning out of the second part of Dad’s original utterance, we can note that in line 4, I only repeat what I have understood from the immediately previous line 3. Similarly to the end of my first scaffold, I end line 4 with a rising intonation, indicating again that I am unsure of my interpretation. Indeed, from being familiar with my interactions with my father and my own thought processes when I communicate with him, I know there is no way I actually believed I had heard Dad correctly: the phrase I suggest does not even make any sense. My suggested candidate utterance “the one who fell out of the swimsuit” thus serves as a metalinguistic commentary to demonstrate to Dad just how uninterpretable his previous utterance was. Rather than providing a genuine summary of my understanding, my scaffold here serves the same function as a clarification request. In looking at the subsequent turns, we see that the scaffold I provide in line 4 is almost completely inaccurate. The only part of Dad’s line 3 that I did interpret correctly is “one,” to which I added, “the” in order to grammatically normalize my question. In line 5, we see that Dad does indicate that my provision of “the one” is a useful scaffold by repeating it directly.

After this repetition, he adds the word, “further,” which he emphasizes by stating it much louder than the first part of his utterance in this line. Dad’s repetition of “the one” may be seen as setting up a normal volume context against which “further” can then stand out as emphasized.

As Dad takes a breath, I use the short break in his utterance to provide demonstration of understanding by repeating, “the one further” with a hanging intonation at the end, connoting that I am now ready to receive the next part of the utterance. Dad accepts this third scaffold and is able to finish his statement by emphasizing East and the “Simp” in Simpsonville, sound clusters which up until this point, I have not demonstrated any understanding of. This segment of talk finishes with me putting together only the predicate section of his question for him, knowing that the scaffold I provided in line 2 was correct.

In this case, my scaffold serves to directly point out to my father what he needs to say next to further my understanding. As Dad does not correct the first part of my utterance, I can safely assume that this part is acceptable to him. This acceptance is tacitly understood by both of us and we do not re-orient to or repeat “what’s the name of” again during the entire conversational exchange.

Looking for the Birthday Cards

Readers may recognize the first part of this transcript from the previous chapter, where I analyzed how Dad and Mom are able to co-construct meaning based on a simple gesture alone. The extended transcript we see here is an excellent representative example of how we use scaffolding over multiple turns to narrow down the possible meanings Dad could be trying to convey. This excerpt differs from the previous example because I ask for two full repeats in lines 8 and 12 before I even attempt to demonstrate to Dad what I have or have not understood. In the previous example, the social situation was entirely different than what we see here. When Dad is inquiring about the name of the town further east from Simpsonville, he is in an excellent mood overall because he has been sitting at the table listening to and participating in the lively discussion of his children and their partners, who are rarely ever home at the same time. In my

experience, Dad's resilience to communication problems in conversations is related to his overall mood. That is, he can tolerate having to take greater efforts to communicate during times when his mental and emotional states are not so fragile. I am generally able to gauge what I will call Dad's "resilience to communication breakdowns." In the previous transcript, I could gauge that Dad would be able to handle my metalinguistic critique on his unintelligibility. In the present transcript, however, my knowledge of the previous interactions that lead up to this moment and the difficulties he is experiencing may have led me to gauge Dad as less resilient.

Readers may recall from the previous chapter that in this excerpt, Dad is trying to look through his bag for birthday cards his fellow clients at the senior day care center made for him. He has been frustrated and upset at our inability to locate these cards for him even though Mom has gone to great lengths already to try to find them. The tenor of this conversation is different from the previous example because Dad is so upset and Mom is exhausted with this topic. My gauge of Dad's resilience to communication breakdowns affects the nature of my scaffolding.

(2.11.06; 10:35-12:00, Appendix C)

D=Dad M=Mom A=Amy

1 D: (*reaching for his bag*)

2 M: We'll look for you cards tomorrow.

(.....*monotone voice*.....)

3 A: I didn't see anything on the table when I picked you up except your cd. (.) which I

4 did pick up=

5 D: °mm°

6 A: and um=

7 D: Betahnufpepagetaranatebutcheguvnedy

8 A: what?

(looks at M)

9 M: *(reaches for Dad's spoon to gather the food on his plate)*

10 D: Nn= (2.0) aghhh hs

11 *(dropping his spoon onto the plate in frustration)*

12 A: (10.0) what did you say dad?

13 D: there were enough people r: around that table to ensure tha tookevnedy

14 A: there was enough people around that table to ensure=

15 D: that ha took everything

16 A: that they took everything?

17 D: that I took everything

18 A: that you took everything?

19 D: °mm°↑.

Co-Constructed Meaning		There were enough people gathered round that table to ensure that I took everything			
Time ↑	17 D		that	I	took everything
	16 A		that	~~they~~	took everything?
	15 D		that	ha	took everything
	14 A	There were enough people around that table to ensure=			
	13 D	There were enough people r: aroun at table tensure tha took evendy			
	12 A	(10.0) What did you say Dad?			
	8 A	What?			
7 D	Bet ah nuf pepa get aran a tebu tche gu vned y				

Figure 11. Looking for the Birthday Cards

Here, we can see that the first two scaffolds (lines 8 and 12) function as clarification requests and engender full repeats from Dad. It is important to note the 10-second pause before I repeat my request in line 12. During this break in the conversation, Dad drops his spoon onto the plate due to the difficulties he is having eating by himself. Mom takes up the task of feeding Dad. My pause can be read as the time I need to assess Dad's current resilience in order to gauge whether or not he will tolerate my furthering this conversation. Instead of being in a good mood as a result of houseguests as in the previous example, here Dad is in a more subdued mood because of the loss of his cards and his inability to eat on his own. The tone of voice I use in line 12 conveys that I am gently trying to re-open the discussion. In contrast to the previous example,

where I repeat what I claim to have heard even though I know Dad could not possibly have said those phrases, here I do not attempt to repeat until line 14, where I am clearly quite close to understanding most of what Dad has said. The hanging intonation at the end of line 14 serves to directly indicate that I only need Dad to fill in the end of the sentence.

In the next turn, Dad does take up this scaffold and simply fills in the blanks of what meaning I am still missing. As I create the next scaffold with a repeat of what I understood from the previous turn, this time I end with a question intonation, indicating uncertainty with my interpretation. My incorrect deictic reference combined with the question intonation allows Dad, in the next turn to emphasize the one word that I still have not correctly understood. It is as though my question intonation has engendered the raised tone of voice. Similarly, in my next turn, I respond to Dad's raised volume on the one deictic term with my own raised volume candidate utterance.

Last Night

In the two previous examples, I focused on what Mom and I were doing to create scaffolds in response to Dad's utterances. The analysis of following example will, by way of contrast, highlight the importance of Dad's contributions to the scaffolding process and to achieving intersubjectivity in general. This example most clearly demonstrates the extent to which scaffolding is a co-construction as Mom, I, and Charles cannot move forward in helping to create Dad's meaning until he increases his efforts.

In the days preceding this conversation, my parents had gone to extraordinary lengths to re-furnish my old bedroom in their house. The room had for years been sitting empty, but in order to give my husband and me a comfortable and private space to stay when visiting, my parents decided to buy a new bed, nightstand and small chest of drawers to make their home as

welcoming as possible for us. As we were going home to visit with increasing frequency, my mother wanted to provide us with a more permanent situation than the pullout sofa bed in the public living room.

My parents spent several days driving around to different stores to investigate product and prices. My mother, in a monumentally athletic feat, moved all the furniture out of her van and up the stairs by herself, taking several breaks and using her body and the stairs in creative ways to ease the task. Because this was a project they started working on together, my father wanted to participate fully in the results of their combined efforts. As he is wheelchair bound, he could not help move any of the furniture nor even walk upstairs to see the process in action or view the results. When my mother had finished arranging the room, the temptation presented by the finished project at the top of the stairs was far too great for my father to resist. He insisted on getting on his hands and knees and crawling up the stairs to see the bedroom. Unfortunately, one of the results of sitting in a wheelchair for so many years is that many of his once-athletic muscles have now somewhat atrophied from lack of use. He also does not display any of his former endurance abilities when trying to achieve a physically challenging task. According to my mother, it took my father about 30 minutes to crawl up to the bedroom, with a short break on the landing to gather his strength. As he does not retain much of his abilities to control where or how his body falls when he tries to lay down, he ended up resting on his side with all his weight concentrated on his arm. Interestingly, my father remembers his trip up the stairs very differently from my mother. As he recalls, his struggle to climb the stairs took hours and his pit stop on the landing lasted about 30 minutes. The following excerpt comes from a family dinner conversation. During the whole day, my father experienced much more severe symptoms of

Parkinson's than usual. My mother, my husband, and I all work together with my father to co-construct meaning in this excerpt.

(6.09.07; 32:15-33:47, Appendix C)

D=Dad M=Mom C=Charles A=Amy

1 D: XXXX⁶

2 M: what?

3 D: XXXX

4 M: You're not putting any air out

5 D: XXXX

6 M: you are=

7 D: XXXX las ni

8 M: what last night?

9 D: XXXX

10 M: what's from last night?

11 D: ah don make me XXXX

12 *(In frustrated tone)*

13 A: (7.0) what about what did you say Dad?

14 *(entering the dinner table area from outside of the patio)*

15 D: XXXX uz last night

16 M: you're like you were last night.

17 D: m like I am because of last night

18 C: because [of last night

⁶The "x" in the transcription refers to units of sound that are completely uninterpretable upon transcription (see Transcript Conventions, Appendix B).

19 M: [Ohhh↓ (1.0) I don't think so.

[illegible]

Figure 12. Last Night

This interchange between multiple speakers illustrates quite clearly how the process of meaning is a negotiated process as four of us have to work with Dad in order for him to express one quite simple utterance. Ultimately, all Dad is trying to say is that “he’s like he is because of last night,” yet this interaction displays 18 turns at talk, over about 40 seconds so that this meaning can be conveyed. Here, the first scaffold serves as the now familiar clarification request that engenders a full (though still uninterpretable) repeat. My mother provides the next scaffold again, but this time her scaffold offers a new platform to build on. In line 4, Mom delivers a metalinguistic commentary as a way of letting Dad know that so far, we as interlocutors have nothing to build on ourselves. Interestingly, Mom’s metalinguistic commentary has the effect of engendering a full repeat. This seems to function as a clarification request of sorts, similarly indicating that we have understood nothing.

Next, in lines 8 and 10, Mom’s scaffolds take on the pattern of letting Dad know what she has understood while also demonstrating where her gap in understanding is. It is interesting to note that here, unlike in the previous two examples, the misunderstood part of Dad’s utterance is at the beginning, yet it still has the form of a clarification request with an indication that Dad simply needs to fill in the blank. Rather than filling in the missing meaning, however, Dad offers a metalinguistic commentary of his own. Apparently Mom has found Dad’s possible repeats threshold: rather than continuing to offer full repeats to help his interlocutors along, Dad withdraws his information and chastises Mom (conveyed through tone of voice) for making him have to repeat himself so much. This creates a chasm in the conversation that is only filled in once I return to the table. It is likely that I did not hear how much Dad was struggling nor the tone of voice that conveyed he was fed up with repeats when I again take up the string of understood words and form a scaffold for Dad. In this scaffold, I do not demonstrate that I have

understood anything at all up until now, yet Dad still responds to my utterance. This time when he repeats, an additional syllable, “uz” is intelligible. This syllable combined with my mother’s years of building her skills as dad’s interpreter are enough for my mother to then take up the scaffolding again even though Dad shut her down previously. Mom’s inaccurate candidate utterance seems to make Dad enunciate a couple additional syllables more clearly, out of which Charles is able to parse “because of” and we are all able to piece together Dad’s original meaning. Mom, Charles, and I are not able to understand Dad’s meaning until he puts forth a greater effort to speak more clearly. Although Mom, Charles, and I can eventually begin to offer the small parts of Dad’s utterances that we did understand, we are left with very little to work with until Dad enunciates and phonates more carefully. This serves to underscore how important Dad’s role is in scaffolding and in co-creating meaning. Even though we have to wait for many turns for Dad to increase his phonation, we do not give up here either. This transcript in particular also serves to highlight the great lengths to which Dad’s family members will go to understand him. We all seem interested in knowing what he has to say rather than dismissing his utterances as meaningless or too difficult to access. Here we see that co-constructing meaning through scaffolding is a multi-party process, where the contributions of all actors, are equally important.

Summary of Findings on Scaffolding

Scaffolding is a process of co-construction as each interlocutor is cuing off of and building from the other’s previous turns. As I began this chapter talking about the creation of the notion of scaffolding within literature on child development studies, let me re-orient to this discussion as I draw the chapter to a close. As I mentioned above, the child development studies generally refer to the roles of the “expert” and the “novice” in reference to scaffolding. There is usually

one person who is more skilled who provides scaffolds for the less skilled member. Recently, however, in both literacy studies and second language acquisition research, there is a trend toward re-thinking these expert and novice categories. For example, Cumming-Potvin, Renshaw, and van Kraayenoord (2003) have analyzed discourse data in bilingual classrooms and have found that even students who are considered to be overall less skilled in a second language are able to provide scaffolds for students who are considered to be near fluent in the language. In their analysis, the scale of their focus was at such a level of detail (similar to my approach) that they witnessed the “less skilled” students providing scaffolds, corrections, and trying to elicit better answers from the “more skilled” students when they were involved in group project work. These authors conclude that the process of scaffolding is more of a co-construction than it is a matter of one person being more advanced or capable than the other.

In my own work, it is important to note that although Dad’s ability to create phonological streams is impaired, it is his meaning that we are trying to understand. That is, he is in some ways the “expert” because he is the keeper of the “answer” we are looking for. Alternately, we could view scaffolding as a process of co-construction, doing away with these categories of expert and novice altogether, instead focusing on how each of us, regardless of roles or positions builds on the other’s turns.

In several papers, Goodwin (2006, 2004, 2003a) draws similarities between his findings and those in the literature that forms the basis for scaffolding: work related to Vygotsky’s Zone of Proximal Development (ZPD) (1978). Vygotsky developed the concept of the ZPD in order to give a more accurate assessment of children’s skills than standardized tests. The ZPD represents a continuum of ability in the child, ranging from what a child can do without assistance to what a child can accomplish with help from an adult or more “expert” person (Guerrero & Villamil,

2000). Goodwin notes that this concept is applicable to his own work only if the unit of analysis is the entire community of speakers rather than the individual. Rather than applying a developmental paradigm to individuals whose abilities are declining, we can draw stronger analogies if we consider the skills of the entire group of speakers to be improving. I conclude by proposing that my family is developing and improving our overall skills in communication as a group even though one member's skills are gradually eroding further each day. Research in this vein has the potential to inspire other families to work toward ameliorating their own communication skills. In this chapter, I have illustrated this development by documenting how my family uses scaffolding to co-construct meaning. In the next chapter, I examine how my family relies on our lifetime of experience of communicating with each other in order to co-construct meaning.

CHAPTER 7: FINDINGS C, LIFE NARRATIVE

Introduction and Organization of the Chapter

As I entered into the analysis of the data for this dissertation, I began to find a pattern in our interactions where people who were less acquainted with my father had much more difficulty understanding him than those of us who have known him throughout the disease. Certainly, talking to him as his disease has progressed has allowed us to become gradually accustomed to his degenerating speech sounds. Through years of conversations, we have trained ourselves to parse words from his phonological stream as we use contextual cues either in the environment or in immediately previous conversations to aid our understanding.

Still, there seems to be another resource we draw on to co-construct meaning with Dad. This is the context we have built during our entire lives that serves as a way of predicting what types of things Dad might say and allows us to find meaning in his sounds when others unfamiliar with his personality cannot. Below, I include a brief story in the section entitled, *Communicating Without a Shared Life Narrative*, that describes an occurrence when a neighbor could not co-construct meaning with Dad because she is not familiar with the stories that have helped to create Dad's present personality and likely conversation topics. I include this narrative to demonstrate the importance of co-created narratives for understanding present talk. Through this story we see that although Dad's interlocutor may be able to eventually uncover Dad's words, true understanding of his intended meaning relies on knowing my father well and knowing the types of things he is likely to talk about.

After this narrative, I provide an example of how shared life experiences are instrumental in making meaning with my father. This section is called, *Successful Communication Due to Shared Life Experiences*. After my analysis of how my father and I came to converge upon a shared meaning, I include a section entitled, *How Shared Stories of the Past Come to Bear on Present Communications* to further explain how a lifetime of shared experiences impact our present processes of meaning making. I then present another narrative that frames the transcripts of this chapter. This story allows readers to see that the meanings we are creating in the transcripts are only part of a story my family has been working on for many years. This section is entitled, *Background to Transcripts in this Chapter: Dad and Bugs* and is designed to give insight into both Dad's obsession with the bugs he sees and his family members' reactions displayed in the transcripts. This narrative also serves to reinforce the image of my father as a jokester. This jokester theme will be relevant to the transcripts at the end of the chapter. After discussing the findings in the transcripts that relate to my family's ongoing story about bugs, I conclude this chapter with two transcripts that demonstrate how family members' familiarity with Dad's jokes and sense of humor is integral to our intersubjectivity. We will see that in order to co-construct meaning with Dad, we rely on our knowledge of the types of jokes he has been telling throughout our lives together.

Communicating Without a Shared Life Narrative

I recall a conversation with my parents' neighbor not so long ago, just after Dad had been released from the hospital and was newly confined to a wheelchair. In a caring and very somber tone, the neighbor, Mrs. M. looked down at Dad and asked, "So now, Peter how are you doing?" I was standing just behind Dad's wheelchair where I had a clear view of Mrs. M's face. In response to her genuine question, Dad answered in a mostly undecipherable stream of sound

while making the motion of leaning back with a drink in his hand. I immediately understood what he was saying, because he was telling a joke I had heard him tell dozens of times before. As soon as I saw Dad make the drinking motion with his hand, I smirked. I could predict the words that he wanted to say to go along with this motion. Mrs. M., on the other hand, looked completely puzzled and asked him to repeat what he was saying. After several repeats, she just stared at him and feigned a smile while saying (in what I interpreted as a rather patronizing tone), “Oh, you did? Well, that’s probably better for all of us then, Peter.”

Dad had been trying to say to her, “Well, I guess I’m alright, but I’ve had to stop drinking and driving because I can’t see the road with my head tilted back.” Rather than accept her serious tone about his new physical limitation, he decided to tell her one of his standard jokes. Yet, even though she eventually understood his words, she never seemed to understand that he was just delivering a joke. Instead, she likely walked away from the interaction thinking Dad really was disappointed to have to stop drinking *while* driving due to being in a wheelchair – a completely absurd notion, to be sure. Now that I have illustrated the failure in communication that can occur when histories are *not* shared, I turn to an explanation of how we *can* call upon our history to create meaning.

Successful Communication Due to Shared Life Experiences

In the transcript below, readers will note that Dad’s phonological stream is severely inhibited. During the entire evening when this conversation took place, Dad was having a particularly difficult time speaking. Charles and I have brought him to the kitchen table to sort through stacks of CDs that were strewn all about the music room in disarray.

I know Exactly What You're Talking About (3.16.07: 30:35 - 31:05, Appendix C)

D=Dad; A=Amy

1 D: un guh un se insi d fugoh

2 A: what?

3 D: between in ne right han side deh cabinet an de duh thi sa uf afeh fi is uhsevee

4 (*pointing in the direction of the music room then trying to use his hands to represent a bag with his hands but accidentally knocking over a stack of CDs*)

6 uh deris u mu mu ic bayou bouhme

7 A: Yeah I know exactly what you're talking about

8 D: yeh aro popi muhses perbos

9 Yes. I know

10 D: Bri ga please

Although it is extremely difficult to hear what Dad is trying to ask me in this conversation, in line 7, I say, "I know exactly what you're talking about," with an emphasis on "exactly" as a way of convincing him. From the event context of sorting through music CDs and from the sounds he expresses in "uh deris u mu mu ic bayou bouhme" (line 6), I seem able to infer that he wants me to get the music bag I bought for him. Yet, these two contributions are not the only information I have to base my understanding on. A couple years ago, I found a special canvas bag for Dad in Winchester, England that has cartoon drawings of composers printed on it. I know that he uses the bag every day to carry CDs and a Walkman to the senior day care center. Although the sound clusters, "mu mu ic bayou bouhme," are not likely to be readily interpretable by other interlocutors, I am able to recover "that music bag you bought me" because I have a shared life history with Dad and the objects he values. I do not even need Dad to repeat this

utterance. This example stands in stark contrast to the story I presented in the previous section where the neighbor was unable to understand Dad even after she understood his words. In the next section, I frame the transcripts in this chapter theoretically.

How Shared Stories of the Past Come to Bear on Present Communications

During the many years of family discourse, there are certain ongoing narratives that we build and re-build, tell and re-tell. Throughout this data set, there are several ongoing narratives formed throughout our lives together that form the basis of our understanding during present conversations.

Goodwin (2004) describes how Chil's family is able to co-tell a story about an earthquake they experienced thirty years previous. Goodwin mentions that after Chil's wife died, many of the stories Chil wanted to tell were lost. She served as the store of his memories of life events that were no longer accessible to him once she had passed. Although Goodwin examines the turn-by-turn processes that Chil and his wife use to co-tell a story, he does not examine how these stories developed over time. Rather than analyzing the process of storytelling in this chapter, I look at how family narratives on a subject develop over an extended period of time and then demonstrate how we rely on these narratives as a way of understanding future and present utterances.

Here I argue that every interaction we have with others in this world is filtered through our previous life experiences, forming a particular frame of interpretation for each future utterance we make or encounter. In a Bakhtinian sense (1986), the meaning of what is said can be understood from orienting to linguistic forms, but the significance of what is said is only interpretable against a background of earlier discourses on these common themes. I propose that my family has its own understandings that can only be understood by those who have been

present during the development of the ongoing narratives in our family life. As Lemke (1995) posited,

Each community and every subcommunity within it has its own system of intertextuality: its own set of important valued texts, its own preferred discourses, and particularly its own habits of deciding which texts should be read in the context of which others, and why, and how. (p. 10)

I argue that my family is a subcommunity with preferred discourses that have developed through time and are understood against the background of previous conversations on the same theme. Now I turn to the background context to my family's conversations about bugs. I then show a series of transcripts that trace the development of this bug storytelling. Throughout the chapter, I maintain that the background of these ongoing family stories are a primary way in which we can co-construct meaning with my father, particularly in ways that are inaccessible to non-members.

Background to Transcripts in this Chapter: Dad and Bugs

When we first moved to South Carolina from Long Island, my father was endlessly entertained by the huge flying cockroaches that the southerners like to endearingly call, "Palmetto Bugs." Jokes about how South Carolinians revered this lowest form of life as their state bird never got old for him. No matter how clean my mother kept the house, it seemed the little buggers always found a way in. My father would sometimes set up a situation where he could surprise them and then laugh as they all scurried away for cover. At night, he would purposely leave out a bit of food to bait them in and then quietly sneak up on them and turn on the lights. He cackled as they scattered, saying "did you hear that? Listen! Those bloody great beasts sound like lobsters running across the counter!!"

After my father was forced into an early retirement by his worsening symptoms, he discovered daytime television for the first time in his life. And this meant he was exposed to a new genre of advertising not typically found in between segments of world news. We all would have been amazed if my father had called up and ordered something along the lines of those free mailing labels advertised on TV knowing that he would probably be too cheap to pay the few cents in shipping. Imagine our surprise then, when we found out he had ordered half-a-dozen cockroach zapper devices to plug into electrical sockets. Apparently the ad claimed that the gadgets converted electricity into an energy frequency imperceptible to all creatures other than the insidious cockroaches creeping through the spaces in the walls. According to my father, the ad explained that this particular electrical frequency was somehow conducted through the inner workings of the walls and was so disturbing to the nervous systems of cockroaches that they would turn right around and run right out of the house.

At this point in his struggle with Parkinson's my father had fallen hundreds of times and needed to move through the house with the assistance of a walker. Wrapping two hands around the sides of a walker was too pedestrian a task for my father, as it meant he could not carry anything along with him. He subverted this limitation by getting grocery bags and filling them with whatever he needed to transport, wrapping the handles around his wrist and then clutching the bars of his walker. One afternoon, I saw him crossing his bedroom with such determined vim, a Bi-Lo bag filled to the brim with some mysterious pile of objects banging violently against the metal legs of his walker as he charged across the floor. "Dad, what are you doing?" I asked in a tone that displayed how absurdly I thought he was acting.

My father stopped to call out his plan: "I'm giving the cockroaches Parkinson's!!! I'm messing up *their* nervous systems!!!" He laughed like a maniac as he made his way across the

rest of the room. Only my father could have invented such a perfectly outrageous game for his own amusement.

This obsession with cockroaches seems to have burrowed its way deep down into my father's psyche, now karmically emerging to play tricks on my father's eyes. One day my mother came home from work to find several of the kitchen chairs knocked over, a melon-sized hole punched through the kitchen wall, and small pools of blood on the floor. When she cried out for my father, she heard him call back from the bathroom in their ground-level bedroom. As she rushed through the house to go straight to him, she found her path cut-off by an overturned sofa in the living room. Once she had righted the sofa, she ran through the bedroom to find my father sitting on a chair, dripping with sweat and trying desperately to wipe his own blood from his shirt before my mother found him. Upon my mother's inquisition, my father seemed not to remember what had happened. He didn't even realize that the blood was coming from a gash near his eye.

After cleaning him up, it occurred to my mother that there could be someone still in the house who had helped create the chaos. As she began her investigation, she realized that all the doors were locked and no windows seemed broken. When she entered my father's music room, she found another hole punched through the wall and a completely destroyed coffee table. It definitely seemed that there had been a violent struggle, but there didn't seem to be any point of entry to the house.

As my parents attempted to reconstruct the events of the afternoon, my father seemed to recall that there had been a person at the back door trying to get into the house. He hypothesized that he may have been moving frantically from room to room trying to hide from whoever was trying to break in. To my mother, who had re-traced the trails of blood throughout the house, it

looked as though he was trying to walk without his walker, fell, and hit his head. She thought that he was then having hallucinations of someone attacking him and was viciously fighting back.

This hallucination theory was reinforced when my father started to claim that there were cockroaches everywhere. He was not just seeing one or two, but piles of them on the walls, floor and countertops. He also claimed that he'd just spoken to his close friend Valerie, who had just been standing in the corner of the living room (even though she lives in England).

By the time I arrived on the scene, my parents had been in the emergency room for hours. As my father lay on the gurney in the hallway, he kept sitting up in a panic, wanting to attack the oxygen tank in the corner. After his neurologist finally came to see him, it was determined that the Demerol given for my father's "routine colonoscopy" the previous day was never to be mixed with Parkinson's medications.

My father was admitted to the hospital, where he stayed for 6 weeks. During this time, he was either caught up in unbelievable hallucinations or comatose. He was almost never in his right mind and was put in diapers by the overburdened nursing staff who preferred this to actually coming when we pressed any of the buttons for assistance. My husband, mother, and I took turns during these weeks sleeping in a recliner next to his bed to prevent my father from hurting himself any further. During the nights I stayed with him, he tried to get up to go to a business meeting in Pennsylvania until I jumped up and forced him back in the bed. On several occasions, he appeared to be holding court with a group of about 10 people lining the far wall of the hospital room. From what I could gather, he was negotiating a business deal through which he would sell them the rights to the book on his life for \$23 million. Throughout the hospital

stay, he continued to see mobs of cockroaches cluttering up the wall, climbing over his food tray, clinging to the side of his drinking cup, and tunneling through the folds in his sheets.

During about the first four weeks of his stay, the doctors and hospital staff had us convinced that “this was it” for my father. When the nurses asked me which nursing home we would be putting him in when he was released, I really started to believe this was the end of the long road. Yet somehow, the doctors re-arranged the medications and through some delightful miracle, my father pulled out of his foray into clinically recognized insanity and slid back into the charming insanity where we have always known him to reside.

After two weeks of grueling therapy routines in a rehabilitation ward, we met with my father’s social worker and doctors who warned us that if he needed to be monitored 24-7 from now on. They seemed to be threatening that if he ever came into the hospital again in such a state and if he was found to have done damage to himself while left alone, he would be taken from our care. He was never to use a walker again, and was instead given a wheelchair. Now things were serious. We were grateful that my father was released to us just in time to spend Thanksgiving at home.

When shopping for Christmas gifts that year, I came across a two-foot long, latex stuffed cockroach, propped up in a lawn chair in a party supply store. He was part of a beach scene, under an umbrella, wearing sunglasses and with one arm poised to hold a fake margarita glass. I’ve always found it impossible to shop for my father, but this year I hit the jackpot. From the second I saw that cockroach, I knew where his new home would be. At this point, my (now) husband and I had only been dating for little over a year and his reaction to my purchase of this gift revealed that he was still not completely initiated into the Heaton household humor. Our conversation went something like this: “I dunno, Amy. Don’t you think that’s a little much? I

mean he just got out of the hospital. Don't you think that's gonna just bring back a lot of bad memories? You don't think that's a little insulting to make fun of his illness?"

"Yes! And he's gonna love it!" I replied. "You'll see."

"Ok, if you say so. I'm sure you know your father better than I do."

When we opened Christmas gifts, I waited to give my father his special present until the very end. I was ready with a camera and hoping that I wouldn't be eating my words. When Dad finally pulled the creature from the box and realized what it was he immediately burst into hysterics. I have a treasured picture of him hugging his new friend (whom he'd named Cedric) on his shoulder like a newborn baby. He carried Cedric around the house on his lap the rest of the day, sometimes propping him up in a chair next to him or attacking my dogs with it when they made the mistake of walking by him.

When it came time for my mother to return to work in January, she had to find an adult day care center for him to attend during the day. While she didn't like the stigmas associated with dropping off one's spouse for the day, she knew that he could no longer be left on his own. Most of the other clients in the center are non-responsive and don't interact much. My mother was very worried that Dad would be depressed there and have no way of making any connections with anyone. My father wasn't happy about it either, but knew he didn't have much choice.

Not long after he started attending the center, I got a call from my mother. She had a story to tell me about Dad. Apparently, he'd asked her to take him into the center a little earlier than usual so he could get there before the director. He had a scheme brewing. He enlisted the help of one of the center's staff and got into the director's office. He carefully perched Cedric on the director's chair, with the front legs resting on the computer keyboard. Somehow he was able

to wrap one of the arms around the telephone receiver to make it look like his little friend was taking a phone call. He then had the staff helper wheel him to a place against the wall where he could look unsuspecting, but still see the director's reaction when she entered her office. He waited patiently for quite some time until the woman came in and started screaming at the top of her lungs. My father snickered in the corner.

My father now has two little cats at home who pounce and ferociously rip the heads off any cockroaches who might dare enter his house. Dad looks on proudly from his recliner.



Figure 13. Dad & Cedric

Examining the Process of Creating a Family Narrative

While the previous transcript entitled *I know Exactly What You're Talking About* demonstrated clearly how sharing a family history can factor significantly in achieving intersubjectivity, this transcript did not show the process through which my family forms a

shared history. The purpose of these next six transcripts is to examine this process and to give evidence that there are ongoing family narratives that we continually draw on. Understanding how a family's life narratives are formed will enable us to see a new level of the co-construction of meaning. Here, we can see how my family co-constructs meaning over several months and also how the meanings we create each time influence the subsequent negotiations of meaning.

Specifically, the next six transcripts display my family's ongoing process of creating a narrative about bugs my Dad sees on his cats. We are still not completely sure whether his visions are part of a visual problem, or hallucinations with a more serious neurological basis. As we saw in the previous narrative, Dad has a history of being obsessed with cockroaches, which he claimed to see everywhere, particularly during his worst period of mental difficulty. Dad seems to have transferred his obsession with cockroaches to an obsession with fleas and mites on the cats. He seems convinced that he sees hundreds of them moving all over the cats and devotes much of our conversations to convincing us of what he sees. The transcripts are displayed in chronological order, to emphasize how a family's narrative develops over time.

The Cats' Ears (2.11.06, 24:10-25:00, Appendix C)

A=Amy; D=Dad

1 A: [did you↑=]

2 D: [Dide]theradid::ediscoverater earsanyway

3 A: Did they what↑ their ears anyway?

4 D: discover there was anything wrong with them.

5 A: discover anything was wrong with them? No. <There's nothing wrong with them.>

6 C: [()]

7 D: [crrer]

8 A: with the cats? or with their ears.

9 D: the cats [(2.0)] ears

10 A: <[no no no no] no there's nothing wrong with them.>

11 D: they got mites

12 A: uh huh °I think° any cat that lives on a farm or doesn't live with any kind of care

13 will have mites (2.0) at least with ter=tess tessie has ear mites.

This conversation occurs during an evening meal just after Mom and I have returned from taking the cats to the veterinarian. Dad is questioning me about the cats' physical exam and is expressing a particular interest in finding out whether or not the veterinarian found mites in their ears. In both lines 5 and 10, I answer him quickly and end my statements with a downward intonation, as though trying to shut down the topic. While this is the first conversation I have captured on video tape, I seem to already have a notion that I need not to allow this conversation to devolve into a situation wherein I exacerbate Dad's worries about bugs on the cats. My added emphasis on particular words and phrasal intonation patterns in line 12 also support the notion that I am trying to downplay the presence of mites on our cats. Here, I try to do this by saying that all cats have mites, so it should be nothing to worry about if his do as well. Shutting down conversations where Dad is insisting he sees bugs is a pattern I have already adopted by the time the events in this transcript take place. The occurrences in the narrative about cockroaches I include above have happened before this transcript so it is possible that these past events are impinging upon my co-construction of meaning with Dad here.

Fleas or Mites? (7.26.06; 3:32 – 4:13 Appendix C)

(Dad has been petting the cat that is laying on the cushion to his left)

D=Dad; A=Amy

mites may be affecting the direction of this conversation as I try in lines 4, 6, 8, 14, and 15 to dissuade Dad from his insistence that there are mites in the cats' eyes. Interestingly, parts of Dad's utterances in lines 1 and 3 are uninterpretable, yet I do not need to do much negotiation with him in order to respond confidently to the contrary in line 4. It is possible that little negotiation is needed here because of our past stories about mites. In the next excerpt, we will see how my debate with Dad over the insects he sees transforms into a debate over purported marmalade on my sleeve. I include this example because although Dad sees something different here, I treat his visions similarly: I try to disprove his claim.

Marmalade or Flecks of Yellow Thread? (3.13.07A; 30:20 – 31:04, Appendix C)

D=Dad; A=Amy

1 D: Amy (2.0) you've got marmalade on your sleeve

2 *(calling me to him)*

3 A: I got Marmite on my sleeve?

4 D: marmalade

5 A: where?

6 *(Walking closer to Dad, holding out sleeves and looking for marmalade)*

7 D: the th there

8 *(nodding with his head to direct me to an area on my sleeve)*

9 A: it's a multicolored shirt

10 *(moving right up to Dad, placing sleeve inches from his eyes)*

11 D: ehh ahh

12 A: that? (.) it's thread.

13 *(pointing to the yellow flecks in the threads of my sweater)*

14 D: eh deh ne tu tu round turn around

15 A: *(turning around a full 360 degrees, right in front of him)*

16 D: ehn de xxxxx no no no t suh fa

17 A: huh? not so fa:st?

18 D: yeah slow down.

19 A: *(turning around again but very slowly)*

20 D: xxxxx se something

21 A: it's just cause it's got these yellow flecks when I move quickly I think it looks like that.

(showing Dad the yellow thread on my sleeve and then walking away)

In this conversation, Dad rather than expressing concern about insects on his cats, Dad is worried about marmalade that I may have gotten on my sleeve while eating breakfast. This is the same type of conversation as the others, where Dad is trying to convince me of what he sees. I am wearing a purple sweater that has other multicolored threads woven throughout. Dad calls me over (line 1) to inform me that I have marmalade on my sleeve. As we try to come to a common understanding of what is actually on my sleeve, Dad has me turn around for him (line 14, 15, 18, 19) so that he can see the yellow on my sweater closely. After turning for him twice, Dad still sees something (line 20). Despite his claim, I tell him he is just seeing the yellow flecks in the sweater and then close down the conversation by walking away.

My definitive ending of this conversation may be indicative of how our ongoing understanding of Dad's visions has developed to the point where I dismiss what he sees. In lines 9 and 21, I am very quick to discount what Dad claims to see. A non-family member or person who does not share this history of frequently debating over Dad's visions may have responded in a completely different way. This theoretical interlocutor may have taken more time to understand

what Dad saw by asking him to describe it in greater detail or by having Dad put his finger on what he saw. Although I go through the routine of turning around so Dad can see the whole sweater and I do take the effort to raise my sleeve close enough for him to see it, during this entire conversation, I do allow Dad to try to prove his point, but I am also concerned with having him accept my conclusion.

It is likely that I do not take his visions seriously because we have had so many previous conversations on similar topics. This conversation is an important part of our ongoing narrative during which we try to negotiate whether or not Dad is “just seeing things” or is actually seeing things that should be of concern to us. Our process of co-constructing meaning is affected by our past debates about Dad’s visions because I am often as concerned with my own agenda and meaning as I am with helping Dad co-construct the meaning he wishes to convey.

The next example occurs less than one month later and is a return to the discussion of insects on cats. We will see in this transcript how I intensify my insistence that Dad does not see what he claims to. Although I do again go through the entire routine of allowing Dad to point out what he sees, I seem to become increasingly adamant that Dad does not see anything.



Figure 14. Looking for fleas on Fizzdale's leg

Fleas on Fizzdale's Leg (4.08.07A; 13:12 – 15:54, Appendix C)

D=Dad; A=Amy

1 D: xxxxx

2 A: what?

3 D: xxxxx le le leg

4 A: he doesn't have a leg?

5 D: left leg

6 A: what about it?

7 *(looking at down at the cat's leg)*

8 D: erh bou by that joint

9 A: what? What about his joint?

10 *(changing the topic to talking about feeding the cat with a bottle 10.0 seconds)*

12 D: ehn ne now hi foot now his foot

13 A: what? that's his tail

14 *(holding up the cat's tail to demonstrate)*

15 D: his foot

16 A: what about it?

17 D: it's cah cauw ing on it

18 A: it's caught?

19 D: in deh uh deh uppermost part

20 A: Do you think there's something wrong with it?

21 *(getting up from a seated position to crawl across the floor to Dad with the cat in arms)*

22 D: eh er eh xxxx top side th ther ther it is there

23 *(looking directly at Fizzdale's leg)*

24 A: it's a toenail

25 D: in his fur

(shaking his head)

26 A: in his fur you think there's something like a flea?

27 D: yeah a fe puh pee pe pee pee

28 A: pee pee?

29 D: yes

30 A: Da::d. you're seeing things. It's just shadows

31 *(the cat struggles to try to get out of my lap)*

31 D: there it is there it goes again.

32 A: Dad it's cause the light's changing. This thing? That?

33 *(pointing to a particular place in the cat's fur)*

34 D: eh um eh no. That that there. Look. Look xxxxxxxx

35 A: that?

36 *(pointing to a bit of fur)*

38 D: eh no um eh that by your thumb now

39 A: here?

40 D: xxxxxxxx

41 A: Dad it's just the light

42 D: xxxxxxxx

43 A: you think he's got pee on him?

44 D: no

45 A: what? flea.

46 D: flea.

47A: oh.

48 D: xxxxxxxx

49 A: oh well I'll get the comb if you want me to comb him (2.0) but I don't know if=

50 *(looking through the cat's fur to find fleas)*

51 D: there it is.

52 A: whe::re? where.

53 *(rising to my knees with the cat in my arms to reach Dad's eye-level)*

54 D: there.

55 *(pointing directly to a spot on the cat, making contact with the cat's fur)*

56 A: Dad that's not a flea that's the way that the hair is.

57 D: moving.

58 A: it's not moving. Your medications are making you see things.

59 D: there's one there look

60 *(pointing directly to a spot on the cat's fur)*

61 A: Dad that's just the way that the tufts of fur allow you to see down into the darker-

62 colored skin.

63 D: eh xxxx mov mov[ing

64 A: [well how come you don't say anything about that?

65 *(purposely pointing to something I know to be a piece of dirt)*

66 D: that's one as well

67 A: it's not (laughing) it's a piece of dirt. You're eyes aren't seeing right.

68 *(retreating back into a seated position on the floor)*

69 D: mm seeing ah pa xxxx f are

70 A: you're seeing things for what they are?

Here, Dad initiates a conversation to discuss fleas he sees on his cat, Fizzdale. Interestingly, however, figuring out that fleas are his concern takes us a full minute-and-a-half to establish (lines 45-47). During the first half of this interaction, Dad is using the strategies outlined by Environmental Indexing- 3, where he vicariously moves through my body. He has me manipulate Fizzdale's legs, joint, foot, and tail while also necessitating that I bring the cat to him for his own close inspection.

Although it has taken a relatively long time to establishing that there is nothing wrong with the structure of the cat, as soon as I realize this is about Dad seeing something in the cat's fur, I start the process of shutting him down. Interestingly, though, while I am continually denying what he is seeing, I am again (as in the previous transcript) going through the entire exercise of letting him point to what he sees. Here I do allow him to build his case more thoroughly, as I even bring the cat over to him (line 21), point to places in the cat's fur (line 33, 35, & 39), offer to go get the cat and comb him for fleas (line 49), and hold the cat directly at Dad's eye-level for him to see clearly (see Figure 14).

Despite these efforts, I still offer the following conclusions: "Dad, you're seeing things. It's just shadows" (line 30), "Dad, it's cause the light's changing" (line 32), "Dad it's just the light" (line 41), "Dad, that's not a flea that's the way the hair is" (line 56), "It's *not* moving. Your medications are making you see things" (line 58), "Dad that's just the way that the tufts of fur allow you to see down into the darker-colored skin" (lines 61 & 62), "It's not it's a piece of dirt" (line 67) and "You're eyes aren't seeing right" (line 67). All of my conclusions seem decisive. I eventually try to trick Dad in order to test what he is seeing. As I point to something I know to be a piece of dirt on Fizzdale's fur, I ask, "Well how come you don't say anything about that?" (line 64). When Dad insists, "that's one as well" (line 66), I laugh at him and tell him his eyes "aren't seeing right" (line 67).

My actions in this excerpt may be interpreted as making an insincere display of co-constructing Dad's intended meaning. Rather than believing Dad, I seem to spend quite a lot of time and efforts to build my case against what Dad is seeing. It is important to note here that I am interpreting these current visions against my background knowledge about his previous clinical diagnoses and my store of personal experiences with Dad's visions. My actions here

might also be interpreted as a sincere attempt to help Dad understand that what he sees is not visible to me or to others in general. Whereas in the last transcript I seemed to close down the conversation relatively quickly, here I take a lot of effort to prove my own case (including playing a trick on him). By the time this conversation occurred, I had had several interactions with Dad in regards to him seeing things that others do not. Perhaps I go to the extremes I do because I feel this time I can actually convince him that what he is seeing does not exist. Our previous conversations on this topic affect our co-construction of meaning here by putting me in a proactive stance toward pushing my agenda of convincing Dad there are no fleas. We do not need to re-construct a general narrative about the basic fact that Dad sees things, because my family has already established this over many years of having discussions similar to these. Our past experiences allow us to start this conversation at a more knowledgeable level. Dad and I are able to continue this discussion in the next conversation I have transcribed. Interestingly, this interaction occurs within the same hour as the previous transcription.



Figure 15. Showing Dad the flea comb

Nobody Else Sees Them (4.08.07 A; 41:20 – 44:15)

(Dad is petting the cat)

D=Dad; A=Amy

1 D: ed de xxx two te two things are there on his back have look at them

2 A: that right there is a piece of dirt=

3 *(coming over to look at the cat)*

4 D: it's moving

5 A: it I just picked it up! (3.0) Dad you're seeing like little black specks somehow

6 *(taking the piece of detritus and showing it to Dad; going to get the flea comb)*

7 D: xxxxxx

8 A: Nobody else sees them

9 *(starting to comb the cat for fleas_____)*

10 D: eh be xxxxxxxx sees xxx magination xx

11 A: I'm not sa:ying it's in your imagination I'm saying=

12 D: xxxx eh nuf my imagination

13 A: you have enough that's in your imagination?

14 D: xxxx have gu xxx my imagination (6.0) xxxxxxxxxx

15 *(30 second pause in the conversation while I comb the cat and Dad looks on)*

16 A: oops. There goed one

17 *(finding a flea)*

18 D: where?

19 A: *(showing Dad the contents of the comb gleaned from the cat's fur)*

20 D: yeah eh yeah

21 *(looking at the comb)*

22 *(I get rid of the flea and then continue to comb the cat while Dad watches)*

Whereas the first part of our previous conversation centered on establishing Dad's specific concern with the cat, this excerpt shows that no negotiation of meaning was necessary here for me to understand that he is seeing fleas. Instead, I immediately insist that he is seeing a speck of dirt (line 2). This lack of negotiation to understand what Dad is trying to say serves to highlight the importance of life narratives in the co-construction of meaning. Here we fall into what has become a standard choreography, where we again debate whether or not he is actually seeing fleas.

Perhaps as a result of our previous discussions, especially the one less than an hour previous to this one, Dad and I take this debate to a more contentious level very early on. My mention of a piece of dirt on the cat in line 2 is not a joke this time. Instead of trying to trick Dad, I seem frustrated that we are still having this same conversation. Dad then raises his voice to me in line 4 when he insists, “it’s moving” and I return his raised tone with my rebuttal, “I just picked it up!”(line 5). I then continue to build my case by saying, “Dad you’re seeing like little black specks somehow.” At this point I actually pick up the piece of dirt and show it directly to Dad (line 6). I then continue with my argument by stating, “nobody else sees them” (line 8).

Dad then supervises while I comb the cat for fleas (lines 14-19). Here our co-construction of meaning is affected by our ongoing story about Dad seeing insects on the cats as I make somewhat less of an attempt to understand Dad’s point of view or meaning. In fact, I do not respond to Dad’s mostly uninterpretable utterance in line 14. I again go through the motion of looking for fleas with no expectation that I should find what he is seeing. However, I do find proof of one flea and I show it to Dad for approval (line 19). The fact that I actually admit to finding a flea by showing it to Dad is interesting. After this finding, Dad does not press our debate further, as though the one flea served to justify his case. I know that Dad is usually trying to convince me that the cats have fleas all over them, yet here I choose not to continue pursuing my agenda of proving Dad wrong. I seem more interested in completely dropping this conversation than I am in continuing the same debate. Although we have not truly come to an understanding about the fleas on the cats, I allow the one flea to end our discussion. Instead of working until we come to agree on what Dad is doing, we both settle on the meaning we have co-constructed for the time being.

The next transcript also comes from a conversation that occurred on the same day as the previous two. Although Dad does not initiate a discussion about insects on the cats, this transcript is part of the same ongoing family narrative because it concerns Dad seeing something that no one else sees.

Next to the Cockroach and the Flea (4.08.07 B; 19:07- 20:25, Appendix C)

D=Dad; M=Mom; A=Amy

1 D: Take the skins away

2 (nodding at his plate, referring to the fish skin)

3 M: There is no skin on there

4 (*reaching over to Dad's plate and moving the food around with a spoon*)

5 D: ze uh xxxx

6 A: see that's where I get it from Dad doesn't like the skin either

7 D: eh the there's a bit there's a bit

8 (*pointing to fish skin on his plate*)

9 A: It's right there next to the cockroach and the flea

10 (*laughing and then looking at Charles, who just looks down and shakes his head*)

11 A: I spend half my time here trying to prove to Dad that there's not 800 fleas on the cat

12 M: and I spend every evening doing the same thing.

13 A: It's when he sees their fur pushed back and it eh ne it has a black look to it and when

14 (*making the motion with my hand of fur being pushed back*)

15 the fur moves=

16 D: the black objects are moving.

17 A: it's the fur moving it's not it's and it's moving in such a way that=



Figure 16. Dad starts laughing at the absurdity of his hallucinations

18 D: *(starting to laugh openly, looking at Mom and Me)*

19 A: Da::d

20 *(all laugh together)*

21 M: the other night he told me it was on my ha:nd

22 *(with joking intonation)*

23 D: was. It was too.

24 A: you said that no but you said that there was some bug on the you saw some bug on
something on the um remote or something the other day

26 D: xxx the leg

27 A: on the leg of the uh chair?

28 D: uh no uh yeah

29 A: of the uh cat? Oh no there was something you were looking at on the phone or something

Much like our conversation above regarding the potential marmalade on my sleeve, this interaction begins with Dad seeing something the rest of us did not. In line 1, Dad tells Mom to take the fish skin off his plate while he nods toward the skin's general location. After mom uses Dad's spoon to scoot the remaining food around in search of the skin, she concludes that there is no skin there. As Dad insists there is indeed skin that needs removal (lines 7 and 8), I liken Mom's search to my previous interactions with Dad where he directs me to find insects for him that only he seems able to see. After declaring that, "[the fish skin] is right there next to the cockroach and the flea," (line 9), I laugh and look at Charles as a way of sharing my joke. Charles, however, shakes his head at me rather than laughing at the joke I've made at my father's expense. As Charles is in training to become a health care provider himself, he likely thinks it is rude to laugh at my father's illness. Also, the fact that he is not a biological family member may still be affecting his ability to know what kinds of things our family thinks are appropriate to make fun of. He is still not completely acquainted with our family's black or dry British humor.

Yet, my joke does not seem to engender a response from anyone at the table. It is as though I have attempted to draw on our shared family narrative about Dad's visions of insects yet no one acknowledges this shared history. My next utterance may therefore be read as an attempt to explain or justify my joke to clearly delineate the connection between the joke and our history. In my explanation I radically claim that, "I spend half my time here trying to prove to Dad that there's not eight hundred fleas on the cat" (line 11). The hyperbolic nature of this comment (or my extreme-case formulation) is a way I attempt to demonstrate how my searching for non-existent fleas for Dad is a time-consuming wild goose chase. Although earlier I received

no confirmation that I was successfully indexing an ongoing family narrative through my joke (line 9), in line 12, Mom states, “and I spend every evening doing the same thing.” Here, she both demonstrates understanding for what I go through with Dad and takes the opportunity to further aggrandize my exaggeration to an every-night chore. Our ongoing family story of Dad and the bugs here becomes one of commiseration between my mother and me.

As I try to explain my understanding of what it is that Dad is actually seeing, I am drawing on our previous discourses about the same topic. As a specific example of how our discourse is a recapitulation of earlier conversations, we can compare lines 61-63 from *Fleas on Fizzdale’s Leg* to lines 16 and 17 of this transcript.

Fleas on Fizzdale’s Legs

61 A: Dad that’s just the way that the tufts of fur allow you to see down into the darker-

62 colored skin.

63 D: eh xxxx mov mov[ing

Next to the Cockroach and the Flea

16 D: the black objects are moving.

17 A: it’s the fur moving it’s not it’s and it’s moving in such a way that=

By comparing these, we see that Dad is repeating his insistence that the “objects are moving.” I also repeat my explanation of what it is I think Dad is seeing. We are still in the process of running through the same choreography. In the transcript from the evening conversation, however, Dad stops me from building my case again fully by laughing heartily at the situation. Dad’s laugh serves as a powerful agent of change to our family discourse about his envisioned insects. With this laugh, he establishes a precedent: he is overtly acknowledging the absurdity of the entire situation. Although he continues to insist that he really does see hundreds

of fleas on the cats (not in transcripts), his laughter may change the direction of our narrative in the future. Dad simultaneously believes he sees the fleas while he also knows (based on the fact that he is the only one to see them, our constant searches for them, and the fact that his medication has made him hallucinate before), that what he sees is impossible and absurd. In line 21, Mom continues with the narrative that has now become a joke entirely by saying that the other night, Dad claimed a flea was on her hand. Dad insists, “it was too.”

These six transcripts concerning Dad’s visions span one year and 2 months. During the year, Dad’s mission has remained consistent until this last conversation: to convince others around him that what he sees is real. In each of the conversations, my purpose seems to have been to deny that what Dad is seeing is real. This family narrative may continue in this same pattern for years to come as Dad never seems to be satisfied with our conclusions and explanations.

A primary purpose of showing these transcripts is to demonstrate clearly how a family comes to “know” what another member is talking about. As Dad’s phonological stream is so severely impaired, we must draw on all the resources available to us in order to understand what he is talking about. These transcripts have also served the simple purpose of showing that my family does have these discourses that are known only to members.

Talk of cockroaches and fleas has proven to be one of our family’s most popular discourses over the years. As we saw in the transcript entitled, *Nobody Else Sees them*, Dad and I do not have to re-establish what part of the cat he wants me to look at when he calls me over. When he utters a mostly unintelligible statement in line 14, I can predict that he is trying to make the case that what he sees is not in his imagination based on our previous conversations about

whether or not his visions are in his mind and based on the phonology that is understandable, “magination.”

Similarly, in *Next to the Cockroach and the Flea*, I predict that Mom’s difficulty in finding fish skin on Dad’s plate is related to his vision problem. While we can interpret the meaning of what he is saying through his nod toward his plate (a case of EI-1), it is our ongoing family discourse about Dad seeing things that no one else does that allows me to attribute a deeper layer of meaning to his talk, thereby releasing Mom of her responsibility to continue looking for something that exists only in my father’s interpretations of visual stimulus. In this situation and many like it, the family narrative about Dad’s visions actually becomes a strategy whereby we co-construct meaning. Instead of having to negotiate several times with Dad, over many turns and potentially many different participants about what Dad could be referring to when pointing to the fish skin, we are able to call upon our ongoing story about what Dad does or does not see in order to make sense of what he is saying.

In the next section, I turn to examples of Dad’s sense of humor and standard jokes as part of our ongoing family story. As we will see clearly in these examples, our past experiences with Dad’s sense of humor and jokes are a resource we use to understand his utterances that would otherwise be uninterpretable.

Dad’s Sense of Humor and Co-Constructing Meaning

In the following two transcripts, we will see how my family relies on our lifetime of experiences with Dad’s sense of humor in order to co-construct meaning with him. For as long as I can remember, my father has been making the same joke about putting shark repellent in our pool. When I was younger, he would come outside to find me swimming in the pool and say, “It’s a good thing I put shark repellent in the pool, isn’t it?” After whatever snide or sarcastic

remark I would make, Dad would retort, “Well, you don’t see any sharks in there do you? Well then.” This joke has become such a standard and predictable part of our discourse that Dad no longer has to tell the joke in its entirety or tell it in a way that the words are entirely recoverable in order for me to be able to know what he is saying.

Immediately preceding this interaction, Dad was trying to scatter the chlorine in the pool himself from his wheelchair. As he took the lid off, he accidentally spilled the chlorine granules all over the Astroturf around the pool instead of scattering them in the pool. The chemicals, in this form are toxic to inhale and my mother is quite upset that Dad has made such a mess. Mom scolds dad for attempting a task he should know he no longer has the manual dexterity to perform adequately. Three of us are now required to clean up the mess he has made doing an activity he should have allowed someone else to do. Mom takes over the task of managing the chemicals while Charles and I clean up the spilled chlorine.



Figure 17. Dad tells his shark joke

Pool Sharks (10.30.05B; 04:00-04:19, Appendix C)

A= Amy M= Mom D= Dad

- 1 A: You act like you're feeding the fish mom
- 2 M: I am
- 3 D: whededh no casee no shaksinapul
- 4 A: what Dad?
- 5 D: whadenuancan asee no sharks xx [pool.] That's cause ah put (2.0) anti-shark
- 6 stuff in the pool.
- 7 A: [I know]
- 8 you put shark repellent in?
- 9 D: yes.
- 10 A: good thing.

Rather than sulking as evidence of his physical incompetence is made even more obvious, in line 3, Dad attempts his joke about the sharks in the pool. Very few of his words seem immediately recognizable. In fact, in the first part of the joke, the only words that sound intelligible are “sharks” and “pool,” after which I say in a monotone voice, “I know.” Those two words, said in the context of Dad and me being outside by the pool are enough for us to co-construct Dad’s age-old joke. While I had not originally considered the added layer of humor inherent in Dad’s timing the joke right after he just tried to put chemicals in the pool (perhaps read as “shark repellent”), it is possible that Dad was also indexing the immediately previous occurrence.

After my monotone response to the first part of Dad’s joke, he continues to tell the rest. Due to the pause and stuttering, it appears that Dad is trying to think of the words “shark

repellent,” but can’t quite find the exact words he usually uses to tell this joke. He does manage to find an alternate way of expressing the same meaning as he says, “anti-shark stuff,” (lines 5 and 6). As I have heard this joke countless times, I am able to find the right words and I offer, “shark repellent?” Here we become co-tellers of a joke that is so much a natural part of our family’s discourse that I only need a couple of words placed in the correct physical context in order to capture his meaning. Without this lifetime of experience with Dad’s sense of humor and this particular joke, I may not have understood what Dad was saying. In fact, in the video, Charles, who did not grow up hearing this joke repeatedly, seems mystified by the interaction. This short excerpt serves as a strong example of how my family co-constructs meaning based on the narratives in our life together. The next example also demonstrates how we draw on our lifetime of experience with Dad’s sense of humor to co-create meaning. This example offers unique insight, however, as Dad is not telling a standard joke but is instead making a joke that is quite original.

I begin this conversation topic about the mealy quality of the squash we are having for dinner. My mother is still in kitchen preparing Dad’s meal and has told Charles and me to go ahead and eat without them. I am likely directing my inquiry to Mom as she is the one who bought and prepared the squash. Although Dad has no squash in front of him yet and therefore has no information on which to base any opinion, he still offers one.

Frost up their Bum (2.11.06; 0:130-02:00, Appendix C)

A= Amy; M=Mom; D=Dad

1 A: what do you think is wrong with the squashes?

2 M: I believe it’s (1.0) was not stored properly

3 D: Frosupumbuh

4 A: What

5 D: Frosupumuthembuh

6 A: first ever=

7 D: Frosupthepum

8 A: (2.0) (*looks at D demonstrating lack of understanding*)

10 D: FROST UP THEIR BUM

11 M: frost=

12 A: Frost up their bum?

13 D: yeah

14 A& C: (*laughing, A looks at C and C looks at A*)

15 A: and I'm supposed to understand that.

From Dad's first offering (line 3), I seem not to understand anything as I follow up his utterance with a request for a full repeat (line 4). After Dad's second repeat of the same phrase, I misinterpret the first sounds and do not seem to get any of the words later in the utterance. My scaffold, "first ever=" has the effect of engendering a full repeat again, likely because I have still gotten nothing right so far. Dad repeats a third time after which I simply stare blankly back at Dad. This look serves to express that I still have not understood. On Dad's fourth attempt, he yells a full repeat rather intelligibly after which Mom understands the first word, "frost," and I am finally able to fill in the rest. In lines 12 & 13, I demonstrate that I finally understand Dad is answering my question to Mom with a silly joke about the squash.



Figure 18. Dad tells a joke with no intonation or facial expression

During this entire exchange, Dad never changes his facial expression nor does he provide changes in intonation that may indicate he is telling a joke. In fact, as Dad gets increasingly louder in his repeats, he seems to be conveying the emotion of anger rather than humor. Although the words of Dad's utterance are understandable by his fourth repeat (line 10), I still request clarification, as the sentence is a strange and original answer to my question about the squash. Dad approves of my understanding with a simple "yeah," followed by a downward intonation. He does not accompany any of this interaction with even as much as a smirk, yet somehow Charles and I both laugh, knowing that Dad is making a joking remark.

My final commentary at the end of the interaction serves as a way of sarcastically pointing out how absurd it is that I should be expected to understand Dad's unique way of answering genuine questions. While it was difficult to figure out his meaning (over the course of 10 turns, with three interlocutors), we ultimately were able to because we know what kinds of things Dad would say as jokes. We have a lifetime of experiencing Dad's sense of humor, jokes, and stories.

We can draw on these experiences in order to co-construct meaning with him when his phonological stream is difficult to understand.

An interlocutor who is not a family member may eventually understand the words Dad delivered, but may not have been able to read his full meaning. This notion is supported by the Charles' glance at my face before he begins to laugh. As a newcomer to our family, Charles still needs to verify that he has interpreted Dad's sense of humor correctly.

Summary of Life Narrative Findings

In this chapter, we have explored many different ways in which a lifetime of experience interacting with the members of my family affects our present ability to communicate. First, I presented a short event I remembered where an interlocutor outside of my family could not understand Dad's underlying meaning because she does not share a history with him. This demonstrated the importance of a shared life narrative to co-constructing meaning with Dad. Next, I provided a transcript of successful communication that occurred due to shared life experiences. Here, even though Dad's phonological stream was so severely impaired, I was able to understand that Dad wanted a particular bag because I was a co-author of the story of the bag as I bought it for him years previous and know that he takes it with him to his senior day care center every day. Next, we examined how other researchers view the process of past stories coming to bear upon present communication as a way of giving support for the concept of the life narrative. The story I presented next gave the background to the transcripts on Dad's visions, as it explains that we have been developing a story in our family about Dad seeing bugs and other visions for many years now. This narrative is designed to give readers better insight into why Dad and I interact the way we do in the transcripts that follow. Finally, I ended this chapter with an analysis of two interactions with Dad where I draw on my history of being exposed to

Dad's sense of humor and jokes throughout my life in order to co-construct meaning with Dad in the present. These final two jokes stand in stark contrast to the interaction I described at the beginning of the chapter with our neighbor who did not have this background to draw on as a resource and therefore was not capable of co-constructing meaning with Dad. Throughout this chapter, I have demonstrated the many ways in which my family both relies on and continually writes (through our discourse) our shared family narratives in order to co-construct meaning. This is particularly important in interactions with Dad as there are often times when his speech is so belabored that our shared history with him is the primary source of our understanding

CHAPTER 8: CONCLUSIONS AND IMPLICATIONS

Returning to the Research Questions

The primary question I sought to address through this dissertation was: how does my family come to make meaning with a member who can no longer make distinguishable speech sounds but retains his cognitive abilities and desire to communicate with others? The more specific questions I was interested in were (a) What strategies and processes do we use to co-construct meaning with my father?, (b) How do we invoke different kinds of context to achieve meaning?, (c) How do our family's meaning-making processes inform linguistic theories?, and (d) How can the insights gained in Linguistics through this research improve our perception and treatment of individuals with disabilities? In this chapter, I summarize how this dissertation has answered the above questions. I then review how this research helps to fill in the gaps in the literature on the speech difficulties people with PD encounter. Finally, I discuss the implications for speech therapy for individuals with PD and their families. Entailed in these implications is the suggestion that those of us conducting research in this area as well as those of us delivering speech therapy services to families coping with PD change our perspective from one that concentrates on the individual's deficits to one that highlights the multiple abilities and competences of a person with PD communicating within his or her family.

Answering the Research Questions

I began answering my specific research questions through the three findings chapters, 5, 6, and 7. In Chapters 5 and 6, I examined the strategies and processes my family uses to co-construct meaning (question a). In Chapter 5, I identified and explored the process of

Environmental Indexing whereby my family is able to use meaningful objects and events in the surrounds to create meaning out of Dad's utterances. As I pointed out through the different categories of environmental indexing, we can create meaning by interpreting Dad's gestures toward objects in the surrounds as meaningful without the co-deployment of a phonological stream. Alternately, we can understand his gestures alongside what meaning we are able to parse from his phonological stream. In this chapter I also identified a category of action I labeled as the "puppet master," where Dad vicariously uses the relationship of his interlocutors' bodies to the environmental surrounds as a means of creating meaning. Finally, I demonstrated how we can interpret Dad's gestures as meaningful while he gives complex directions for acquiring objects that are not co-present with us.

While I based my work on Goodwin's body of research on Chil (2006, 2004, 2003a, b, c, 2000a, b, 1995) who had aphasia from a stroke, in Chapter 5, I was able to identify categories of action unexamined by Goodwin, primarily because the pathology of stroke does not manifest the same abilities and limitations. For example, Chil is not able to produce more than three words, whereas my Dad can. Thus the process of co-creating meaning through a combination of a mostly impaired phonological stream and gesture (EI-2) is not addressed in Goodwin's work. Also, the category of action I identified as the "puppet master" scenario is not addressed in Goodwin's work, as Dad still uses his (though very limited) ability to make some distinguishable words in conjunction with our bodies to make meaning.

In Chapter 6, I also answered question (a) through an examination of scaffolding. In this exploration of scaffolding I outlined in detail how my family builds on different parts of my Dad's utterances in order to co-create meaning. Here, I examined the process through which we demonstrate to Dad what parts of his utterances we have understood, thereby indicating to him

what parts of his utterance need to be filled in. The findings in this chapter also promote an expanded view of scaffolding, as the data suggest co-construction is a more apt portrayal of the negotiations through scaffolding than the “expert” and “novice” distinctions. Through co-construction, we can view Dad as an equally competent and necessary contributor to conversations

All three findings chapters (5, 6, and 7) answer question b about the different kinds of context my family invokes in order to co-construct meaning. In Chapter 5, we saw that the physical contexts of the environment in which communication takes place factor in significant ways in our understanding. In Chapter 6, I demonstrated that the context of previous utterances serve as context for our next utterances. In Chapter 7, I showed how the our entire life history of making meaning together as a family is crucial for understanding present conversations. More specifically, I explored how this process of building a historical context occurs and how this in turn serves as context itself. This life context allows my family to create meaning in a way that members outside the family would not be able to. This privileged access to context allows us to uncover Dad’s meaning more readily.

This dissertation informs linguistic theory (question c) by demonstrating how language is a process of co-construction of meaning. This data set and the analysis show how language is not a process that occurs in the mind of one individual that is then transferred directly to the mind of an interlocutor. Instead, language is a social process that occurs through many complex negotiations and interactions. This dissertation has also shown that the human language ability is not merely the ability to do syntax and to make hierarchically ordered speech sounds that are readily interpretable as distinct words. As Dad’s ability to make these discrete, distinguishable sounds that are the basis of words is so severely impaired by PD, the analysis of our

communication with him illustrates that the ability for language entails many additional processes. Dad's actual ability for language resides within the interstices between individuals rather than merely within a distinct and identifiable portion of his neural substrate.

In answering question d, this dissertation has shown that the new insight on linguistics can better our perception of people with disabilities. Accepting that Dad's ability for communication resides in human interaction rather than in a damaged place in his brain allows us to see that he is still a competent social actor. Viewing language as a co-construction process suggests that there are ways in which families can communicate with a person with PD. This promotes a more humane perspective on people with PD, as their abilities rather than their deficits are emphasized.

Filling in the Gaps in the Literature

In Chapter 2's review of the literature on neurogenic speech disorders, in the section entitled *Areas for Advancement of Research on Neurogenic Speech Disorders*, I identified areas where research on people with PD could be advanced. Through this dissertation, I have helped to fill in the gaps in the literature by creating a database that is much more comprehensive than those of the past, where only 10 minutes of conversations with people with PD were analyzed. This data set was recorded exclusively in the home of one family, which has provided access to real-life communication situations rather than the more sterile and controlled environments offered by research done in clinical settings. This present research has also looked at the strategies we use on a much more detailed level than the research done previously that did not examine the turn-by-turn deployment of actions. Whereas other researchers identified categories of conversational action used by non-impaired partners of people with PD such as "facilitatory," "confrontational," "acceptance," "avoidance," (Whitworth et al., 1999), I have examined the

strategies people with PD use in conjunction with their speech partners to co-construct meaning. The actions I have identified are also described at a much greater level of detail. By examining this data through the lens of co-construction, I am able to give a more complete understanding than research done in the past that focuses primarily on the role of the non-impaired interlocutor. Co-construction allows us to see the role of individuals with disabilities as a significant factor in influencing and creating the interaction that takes place. This is another step toward treating people with disabilities as full participants in life.

This dissertation has also advanced research on assessment of speech in individuals with PD as I examined my father's communication ability as it is embedded within his most common social matrix, his family. This is in contrast to earlier research on people with PD that assessed the individuals' abilities in isolation from their usual community of speakers. Finally, the purpose of this research departs from previous work in that this dissertation focused specifically on identifying the strategies we do use to communicate rather than using impressions of speech ability merely to determine the overall stage of the disease a person is currently experiencing.

Implications

Clinical speech therapy can benefit from the findings in this study in several ways. Rather than viewing people with PD as necessarily disabled, clinicians are invited to view people with PD as extraordinary. It is my contention that those who are often viewed through a deficit perspective as being disabled are actually pushing the limits of the human language ability to new extremes as they use alternative means of communicating in their daily routines. As Ramsberger and Lise (2003) point out, "People may have physical, mental, or emotional differences from some norm, but the degree to which a person is disabled by those differences depends on the interaction of that person with the world in which he or she lives" (p. 283). This

statement highlights our responsibility to create a world for people with such differences that is more accepting and encouraging. If we create speech therapy protocols that focus on enhancing and nurturing the communication strategies that people with PD and their families can use, we can strip away the label of disabled. I believe this is a much more humane way of approaching therapy for people with PD than trying to train continually degenerating articulators.

This dissertation has also demonstrated the extent to which a person's ability to have successful and meaningful interactions relies on their familiar speech community. It is my hope that this research will encourage speech therapists to develop protocols that help train the functional language skills of the closest family members and friends of people with PD. If we focus on providing therapy services for individuals with PD in conjunction with their families, we can begin to let the speech skills of these small communities grow and evolve. In this way, families will actually be improving overall abilities to communicate rather than focusing on what an individual lacks. Speech therapists can begin to see the skills that a family creates as a resource. For example, therapists may be able to call upon more experienced families for contributions and suggestions during group therapy sessions with families who are at the beginning stages of managing the disease.

Although published in 1973 in the *Journal of Nursing*, Elizabeth Erb's article entitled *Improving Speech in Parkinson's disease*, which I reviewed in Chapter 2 contained many of the same implications as my own research. In this article, Erb described the exercises she and her colleagues developed to help improve the speech of individuals with Parkinson's disease. Rather than relying on quantifiable measures of whether or not her exercises would have a significant effect on her patients, she built her routine around her own common sense understanding of what her patients' needs were and then appealed to her own intuition in order to know whether or not

the exercise routines were having a positive effect. One of the primary components of her routine is to have her patients participate in group discussions about topics that interest them. In this way, they can practice applying their breathing and vocal apparatus exercises to everyday conversational situations. The main implication of Erb's article is that we can use our common sense intuitions to do small things to help people with Parkinson's to participate more significantly in conversations. Erb was motivated to develop these protocols because she cared deeply for these individuals she saw every day.

Similarly, my research suggests that there are many things we can all do to help people with Parkinson's and other speech disorders. As my mother commented on the findings in this dissertation, she pointed out that her own mother was only educated up to the eighth grade, yet she was able to facilitate conversations and activities with Harold in ways that demonstrate an intellectual maturity and compassion that doctors and therapists working at the state institutes in Indiana may never have exhibited. Although the doctors who evaluated Harold said he would never walk, my grandmother took extraordinary efforts to ensure that he did learn this basic skill. The state psychiatrist who tested Harold said that he could be admitted to a state institution where he would be taught certain skills, but recommended that the love and support of his own family would likely provide a much more productive and meaningful life for Harold. My mother noted that both of her parents communicated with and included Harold in all their daily activities even though this was often difficult. Finally, my mother pointed out that all the facilitatory strategies her parents used with Harold and that she now uses with Dad came naturally. They did not need any formal training or a high level of education in order to treat a severely handicapped family member as "normal."

Much like Elizabeth Erb and her colleagues, the several generations of our family have found ways to interact meaningfully with members with neurogenic speech disorders. This notion that people do not need to be trained to speak with individuals with speech disorders would seem at first blush to contradict conclusions drawn above that families should be involved in group speech therapy. What I glean as an additional conclusion in support of speech therapy, however, is that what some families may need is training that encourages them to consider their common sense and natural communication tendencies as valuable. In valuing the work families do to help their otherwise impaired members, therapy can also take the form of support networks, promoting and supporting the continued efforts of family caregivers and communicators.

Finally, this research suggests that due to the sedimented meanings of our familiar homes, families managing this disease could benefit from therapy that takes place in the environment in which they will need to function. In this way, people with PD can retain their connections with and dignity within an accommodating world rather than withdrawing into a social vacuum.

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APPENDIX A: HAROLD'S LEXICON

Cat: "meow, meow"

Dog: *(a clicking of his tongue against his gums while holding his hand out as though calling a dog to him to be pet or fed)*

Pig: *(moving his tongue in and out of his mouth, as though imitating the suckling action of a baby pig while holding his hand out with imaginary food in it)*

Tractor: "pimm pimm pimm pimm" *(indicative of the puttering noise made by the tractors that were used on the family farm at the time)*

Gloves: "mmmm.mmmm.mmmm" *(moving his interlaced fingers back and forth as though pushing the web of cloth in between the fingers on his imaginary gloves deep down into the inter-digital space to secure the gloves tightly on his hands)*

School: "mmmm.mmmm.mmmm." *(rubbing his index finger from one hand rapidly back and forth in the palm of the other, imitating writing)*

Teacher: "mmmm.mmmm.mmmm." *(tapping his index finger lightly against his eyelid, as though indicating 'someone he is supposed to watch')*

Zoo: "woo woo" *(imitating the sound of the 'train' whistle that ferried guests around the zoo)*

Soft drink (machine): "bip," *(pressing his thumb against his closed index finger, indicating pressing a button)*

Church: "dum dum" *(making his hand into a pointing gesture then moving his hand and arm up and down to indicate ringing of the bells)*

A visitor staying overnight: *(A snorting sound indicating snoring or sleeping made while patting the arm of whomever is staying)*

My name/my mother's name: "ooolll" *(sticking his tongue far out, indicating vomiting or crying)*

Mom, Dad, anybody whose attention he needed: "mama"

Uncle Randy: *(huffing air out through his nostrils and mouth, indicating Smoking, as uncle Randy smoked a pipe for years)*

I'm/It's Cold: "brrrrrrr" *(taking one or two hands and rubbing them on his shoulders)*

I'm/It's hot: "shweeeh" *(swiping his hand or forearm across his forehead, imitating the wiping of sweat)*

Shaving: "mmmm.mmmm.mmmm" *(rubbing either his open hand or his hand made into the shape of a fist across his face)*

Taking a bath: "mmmm.mmmm.mmmm" *(rubbing his chest vigorously as in a scrubbing motion)*

Going to pee: "puswuswuswu" *(imitating the sound of peeing)*

Going to do a bowel movement: "uuuuuugh" *(imitating the sound of having to strain to push)*

Sleeping: *(A snort, as though imitating the sound of snoring)*

Going to town: "bye bye bye bye"

Making a sandwich: "mmmm.mmmm.mmmm," *(placing his left hand out with his palm up and then moving his right hand back and forth over the left, in a spreading motion)*

I/you/she/he hurt(s): "Eh, Owww," *(pointing to the area that is hurt)*

Eating/I'm hungry: "Eh, um"

Drink/drinking: "dud-dee" *(while making the hand motion of having something to drink)*

Come here: "Eh" *(folding his fingers and hand back toward himself in a beckoning gesture)*

Sit next to me: "Eh" *(patting his hand on the seat next to him)*

I want to tell you a secret : "shewupeshweup" *(a varied sound cluster each time, as no 'real' secret was conveyed, while putting his hand on the side of his mouth beckoning to his interlocutor)*

You should/you are go/going home on a plane: "zzzwwwweeeuh" *(quickly)*

*drawing an arc over his head
with his hand, as though
signifying flying overhead)*

Go to Hell/Screw you/Shut up/I have the last word: “Puh!!” (*sometimes
expressed with a
dismissing downward
hand motion*)⁷

Indeed/ I agree: “Uh huh” (*stated with varying tones to connote different
meanings*)

Get out of my way: “beep beep,” (*making the motion of shooing others out of
his way*)

I’ll do it: “Eh, Ahday, Ahday” (*tapping himself on his chest with his fingers*)

Me/mine: “Um uh huh” (*tapping himself on his chest with his fingers*)

Can you give me that/some: “nyuh nyuh nyuhnyunyu?” (*pointing to the object
desired*)

No/I disagree: “uh uh uh uh uh uh uh” (*shaking his head*)

Dead/fall down/tired: “Dahdh” (*slamming one fist into his other open palm*)

Universal sound cluster employed with different tones of voice, depending
on the context: “nyuh nyuh nyuhnyunyu”

⁷ In the commentary my mother gave after reading this dissertation, she mentioned that this term “puh” started out as a term of endearment between her and Harold when they were growing up. As their bedrooms were next door to one another, when they went to bed at night, they started a game whereby Mom would say, “Goodnight, Butchie” and then his response would jokingly be, “puh.” Harold would then say, “Bye-bye,” (his way of saying “goodnight”) and then Mom would respond by yelling, “puh.” According to my mother, they would try to get away with as many iterations of this routine as possible before their parents ended their game and made them go to sleep.

APPENDIX B: TRANSCRIPTION CONVENTIONS
(Adapted from Have, 1999)

↑	temporary rise in pitch
=	utterance not completed
◦word◦	softer than the surrounding words
(<i>writing in italics</i>)	actions related to the talk
<u>WORD</u>	yelling
?	rising intonation, as in a question
(4.0)	seconds of pause/silence
(.)	micropause
a::n	first sound lengthened
<u>word</u>	emphasized word
[words]	overlapping words
.	drop in intonation, as at the end of an utterance
< >	words stated in rapid succession
XXXX	unintelligible utterances

APPENDIX C: CATALOGUE OF VIDEO FOOTAGE

4.22.05

As soon as I turn on this tape, Dad starts with a joke that requires scaffolding in the form of multiple clarification requests in order for me to understand him. His joke is that, “the camera will make me beautiful,” which he delivers with a complete deadpan expression on his face.

I remind Dad of our earlier conversation when he used an expression I didn’t understand. I bring it up presently to request an explanation of the idiom. He recalls “needs must as the devil drives; I ask him how he knows this expression and he explains where he learned it, what it means, and why it’s funny to him.

I take a phone call from mom from 1:40-3:00, during which Dad is completely quiet. Mom reminds me that there is a storm coming, so I get up to go close my car windows. At this point (3:16), Dad starts a new topic of conversation by saying I need to “take it back”. I don’t understand what he is referring to, so I request several clarifications. It turns out that Dad is concerned about the imperfection brought to my filming as a result of Mom’s call. He wants me to rewind the tape so that we can start our conversation over. This is interesting in that it demonstrates Dad’s misunderstanding of my research enterprise and may serve as an explanation for why he seems to be taking such painstaking efforts in this tape to speak so clearly and to correct himself as he goes. I explain to him that the purpose is just to keep the tape rolling and catch all our speech, not worrying about ‘lost’ tape space. Even after my explanation (3:52), he starts back in telling me to rewind the tape to where we stopped having a reasonable conversation. I again explain that I will just edit the tape later.

At 4:10, I start a conversation about the bell Dad has by his chair that he can use to call Mom if he needs help. It seems as though I’m just looking for topics of conversation (seems stilted, not natural). He accepts my topic and talk and tells me it’s for where “shouting can’t be heard,” which I misunderstand as “where Shirley can’t be heard”. We negotiate this one misinterpreted word as I repeat what I understood and let Dad correct “Shirley” through an increased volume on “shouting” during his repetition (**scaffolding**).

At 4:40, I initiate a discussion of typing a letter to Dad’s friend. Throughout most of this conversation, Dad’s speech is relatively careful and understandable. Anytime I don’t understand him, I repeat the part I did get and either end with a “what?” or a question intonation.

At 5:56, I start a conversation about seeing my parents’ minister in the mall shopping for shoes for her trip to Hong Kong. I again use the strategies of repeating with embedded questions for clarification during this talk (**scaffolding**). Dad contributes by saying the place is run by communists. Our conversation turns to the U.S. relations with China. Dad then changes the topic to talking about leadership and industrialization. I seem to follow him with no problems. Then I contribute by talking about outsourced computer help desks in India. Dad says India is nothing

like it was even ten years ago. At 10:20, I repeat part of what Dad has said with question intonation, to which he responds by correcting my one wrong word. At 10:29, I change the topic to talking about the minister of science from Egypt who came to stay with my brother and me for a week. I tie this to the ongoing conversation by talking about how Egypt had a development boom and that now this visitor of ours says it takes him 3 hours to go 15 minutes to work. Dad talks about traffic in New York City.

At 12:30, I start talking about planting seeds, rain and Mom and Dad's lawn. It seems like I'm looking for conversation topics. Again, at 13:24, I repeat what I have understood of Dad's speech with "what" at the end, indicating what meaning I'm still missing. I start talking about hydro-seeding.

At 14:50, I ask Dad how many times he'd watched my Annie tape from the 4th grade (it's sitting out). We start talking about my poor singing during the play. Then I abruptly change the topic by saying, "So, you don't want to go to the Peace Center thing tonight?" We start talking about the musical "Oklahoma" that is playing that night. We talk about musicals and plays neither of us like. Again, it seems like I am talking about so many varied topics because I am just trying to keep the conversation moving for data collection purposes. It seems stilted rather than natural.

After a 15 second silence, Dad starts (17:50) talking about his sharp memory of things that happened a long time ago. I don't interrupt as he talks until about 18:40, when I repeat and summarize what he has been saying about India's history to see if I understood the gist of his meaning. He goes on to talk about obscure minutiae of history to demonstrate to me all the detailed things he can still remember.

At 20:00, Dad sighs and shows frustration with talking for so long.

At 20:10, Dad starts a discussion about my upcoming wedding and Mom's wedding dress that I'll be wearing. We go on talking about my wedding dress plans and Dad is concerned with the money I have spent on fabric for making a dress.

At 22:10, I mention that Mom has scheduled a week of vacation for the week of my wedding to which Dad replies, "I'll schedule a week as well." I immediately interpret this as a joke and laugh heartily even though Dad doesn't smile during the delivery of the joke. I say that they'll miss him at the center. Then I turn the topic to talking about the people who attend the center with him. He tells me about the peoples' situations that have led them to be at the center. He says he can't understand what other people are saying, to which I respond by asking for clarification (with an air of surprise in my voice, indicating that I can't believe it is they who are not understandable). He says some of them can hear things from clear across the room and makes a joke about how they burst into "long laughing sessions." He says he can't understand them because they're so quick and quiet. I repeat this (comprehension check) to make sure I understood correctly. He says the other people all seem to understand each other. When I ask him what he does most of the day (24:40), he says he sleeps most of the day. He says there is a TV room but that the "television is turned in such a manner that only about 10 people can see it". We continue talking about where the center is located, how far it is from Mom's office, etc.

At 26:30, I hear thunder outside and say I am going to call Mom about the storm. I turn off the tape at this point.

Overall, during this tape, Dad's utterances are relatively easy to understand, even though we are having conversations about abstract, complex topics. He seems to be taking a lot of efforts to speak carefully and calculatedly, enunciating difficult sound clusters clearly.

10.30.05 A

This tape begins with a discussion of where I got the video camera. Dad does not understand how a professor can lend me a camera without lending one to all her students. We take a while to sort this out, using several different scaffolds.

Around 2:00, Dad begins explaining something to me about how his stocks have been revalued, but even though I try to use scaffolding to understand him I don't understand until he yells at me. We continue our discussion about "managed share" stocks, which is something I am entirely unfamiliar with, so I am still using scaffolds to get Dad to specify what he is talking about. We are also orienting to the printed list of stock quotes and the computer screen (Dad is pointing a lot to specific lines on both) in order to understand each other (**EI-1**). This discussion of stocks is Dad's way of finding out why all the shares for a particular investment firm have been revalued. Throughout this conversation, **scaffolding** figures prominently because we are talking about something that I do not understand. Dad is having to teach me certain foreign concepts while we make our way through the task he wants me to accomplish.

We experience a few problems due to the old age of the computer and then Dad and I laugh about George Bush going for another term in office.

At 22:41, we decide to go outside to start the chore of closing the pool for the winter. Around 25:00, Dad makes some commentary about needing to replace the Astroturf, but I do not understand what he is saying until he uses his whole arm to gesture toward the ground (**EI-1**). Around 29:00, Dad starts telling Charles where to find the screws he needs to accomplish a chore on the screened patio. He is using a great deal of pointing and gaze in order to help Charles recover the screws (**EI-1**). At 38:05, Dad starts trying to direct me to fix a bit of Astroturf that is hanging into the pool. I can't understand him at all at first and I try to use several scaffolds to figure out what he is asking me to do. Eventually, I orient my gaze where he is looking and figure out his meaning.

At 42:00, Dad and I have a similar interaction, where he is directing me to get the thermometer out of the pool for him. I am unable to recover his meaning until I start to look where he is pointing and looking himself (**EI-1**).

This tape ends with Dad feeding the dogs an entire bag of biscuits. He actually uses pointing quite a lot with the dogs to direct them where to look for biscuits he has dropped on the ground. At one point, Dad accidentally drops the entire bag and has to talk to and negotiate with the dogs to recover all the biscuits.

10.30.05 B

This tape is a continuation of our chores outside, working to close the pool for the winter. As the tape begins, Dad is directing me to get the chlorine bucket from the pool house and as he is struggling to talk, he shows his frustration with gritted teeth, yelling, and saying, “oh God!” in the middle of other phrases. He is the only one in the family who knows what chemicals need to go in the pool and in what amounts. At 00:55, I bring to him a candidate bucket for approval but he says it’s not the right one. Mom also brings two huge buckets over to Dad to show them and gain approval, but he says no to both of them. We are able to understand him based on our working life narrative of doing this (and other similar) chore(s) together over the years. We have at least heard the names of the chemicals before. Also, we are in the physical space around the pool and pool house, so our potential semiotic fields are limited. At 1:52, I find what Dad has been describing and bring it to him saying, “You were right.” He takes the jug of chemicals into his hand at 2:08 and then Mom says (from the background, out of view), “Don’t get that on you, Peter.” I then suggest, “If you want to just instruct me how to do it I can.” Dad’s response is inaudible, but he does continue to hold onto the jug as I move him over to the poolside. He then works to unscrew the lid. I turn off the camera presumably to move it closer to my subjects as the microphone can’t pick up Dad’s speech from the other end of the pool. While the camera is off, Charles somehow acquired the jug of chemicals. Apparently while the camera is off, Dad attempts to scatter the chemicals into the pool himself but he messes up and spills nearly the whole jar of powdered chlorine all over the turf around the pool. As Charles is asking Dad how to disperse the chlorine in the pool, Mom comes into view saying, “Charles, Charles, let me have it.” When I protest saying, “Charles can do that,” Mom replies with “I know Charles *can* but I don’t want it on him.” Mom proceeds to make her way around the pool scattering the chlorine. Right after she scatters it into the deep end, I comment, “You act like you’re feeding the fish, Mom.” She responds with a lackluster “I am,” (3:56). At 4:00, Dad starts to tell an age-old joke that I have heard over and over in my family growing up. He says that it’s a good thing he put the anti-shark stuff in the pool. I rephrase this joke-telling by saying that he put shark repellent in and then agree that it’s a good thing he’s done this. There is nothing in the tone of either of our voices that would connote to an outsider that we are co-telling a joke, but we know this is a joke between us as Dad has been telling this same joke since we first moved into the house when I was ten years old. Our understanding here seems to rely heavily on our **life narrative**, but also on our physical relationship to the pool (**EI-1**). I also use scaffolding techniques to help him co-tell the joke.

At 4:50, Dad is trying to direct me to fixing certain screens on the pool enclosure. He is using pointing gestures and his gaze to coordinate with me (**EI-1**). I wheel him over to where I think he’s looking but then he says, “no,” and points and looks in completely the opposite direction. Around 6:20, Dad accidentally rolls himself into the screen he’s just told me is busted and needs repairing. At 6:40, Mom points this out to him and he moves himself away from the screen his chair has been poking. At 7:47, Dad gives a directive or suggestive to Charles, but it is mostly inaudible and unintelligible due to the placement of the camera and surrounding activities like the hose running.

At 12:50, mom comes out to give Dad his medicine and water.

At 15:26, Dad is trying to direct us on how to roll out the pool cover but we seem to ignore him.

At 22:00, Charles show him one of the pool cover weights and the holes in the back before he goes to throw it away. It seems that he needs to make a case for throwing it away (i.e. get approval). At 27:17, Charles walks by Dad carrying one of the cover weights filled with water. He comments that it looks like the python they saw on TV that morning. Dad says in response, “yes, one called Monty.” This is a joke based on our **life narrative**. He and Charles both laugh together.

At 28:10, I ask Dad if he’s ready to go inside yet, as most of the activity is winding down outside. Before he is ready to go, he points across the pool to another chore he wants me to do.

Our activities next take us into the music room. Dad is trying to listen to music while also directing us where to go to get the antique lamps he wants to give to us as a present. We are working through how to assemble the different parts of the lamp. Dad is using pointing and gaze (**EI-1**) to direct us and we are also relying on our life experience with these lamps to understand the obscure vocabulary associated with their assembly. At 33:00, Dad tells Charles to try turning the wick and the switch. He points directly the levers. At 34:20, Dad uses his hands to demonstrate two parts being held together by a soldered joint. Charles uses **scaffolding** to understand him here as well, saying what it is that he understood so Dad can correct the misunderstood bit. At 37:30, Dad points to a “shade” and tries to get Charles to get it for him. Charles, not sharing in our **life narrative** in regards to these lamps, has difficulty understanding and Dad has to keep pointing and paraphrasing until Charles realizes what a “shade” is. Dad is clearly the expert on these lamps and Charles and I are fumbling to understand what we are supposed to be doing for him. I keep leaving the room to go to the storage shelves in the garage where Dad is not capable of going. On each trip, he requires a report and description of what I found so that he can direct my next actions from a more educated standpoint (**EI-3**). Dad uses idiosyncratic or British phrases at 43:30, which I think I can understand because I am used to his phrases. At 45:00, Dad is attempting to give directions to Charles about how to transport the lamp; I use **scaffolding** to help Charles understand what I’ve understood (also **life narrative**).

At 45:25, Dad tries to draw Charles’ attention to a particular lamp, but Charles has already begun turning him around in his wheelchair, so it is difficult for Dad to point directly where he intends to. Interestingly, Charles’ hands become Dad’s way of pointing as Dad directs Charles while Charles uses his own hand to point at the lamps he is near (**EI-3**). Near the end of this interaction, it becomes clear that Charles has no idea why he is even looking for the particular lamp.

At 48:20, Mom comes in and seems upset that Dad has directed us to take a lamp that is part of a set. Dad (49:12) and Charles are the only two who seem to understand what they are doing, since Charles is having to mix-and-match components from different lamps per Dad’s request. It takes us several minutes to sort out an understanding of Dad’s intentions for the antique lamps in the house. At 52:18, I ask Dad if he wants me to take him out of there, but he points to another area of the music room and says he wants me to take him over there (**EI-1**). He goes directly into a drawer and finds the lamp wick that Charles has been looking for during this entire tape. At 54:00, Dad tells Charles how much of the wick to cut off; Charles checks his comprehension and

then does as he's been told. At 56:40, Dad tries to show Charles exactly how to thread the wick through the lamp base (**EI-1**). He takes it from Charles and does it himself. Dad then starts telling Charles how to re-assemble the lamp parts that are left over. When he seems satisfied that we are doing what he's asked, he goes over to the stereo and starts trying to put music on by himself. He doesn't ask for help from anyone; he even wheels himself over to the stereo system on his own. At 1:01, Dad asks if we're leaving tonight and we say no we've changed plans. Apparently we didn't tell him about our change in plans. The tape runs out as we are finishing packing up the lamp to take home.

2.11.06

This is a birthday dinner celebration for my father. Charles, Mom, Dad, and I are all eating together. At 1:22, Dad starts a request for wine by looking at my glass of wine and saying, "Is that all the wine you got?" (**EI-1**), which I don't immediately understand. After the conversation about the wine bottle being empty, I ask what is wrong with the squash, to which Dad responds, "Frost up their bum." He gives no hint that he is telling a joke and none of us can understand what he says the first, nor second, nor even third time he repeats himself. Eventually we understand that Dad is telling a joke based on our shared **life narrative**.

At 2:30, Mom insists that Charles and I start eating while she is still preparing Dad's dinner in the kitchen. I ask if the cats have ever had steak, to which Dad replies, "we're having steak?" After I say, "what did you think we were having?" Dad says, "I can't see." As Charles and I have our steaks in front of us and have been told to go ahead and eat, I attempt a joke saying, "*We're* having steak, but I don't think *you* are...you're having Tofu." This is meant to be funny because my Dad would never consider eating any kind of soy meat substitute (life narrative). Dad doesn't laugh at all.

At 6:08, I comment on the steak, saying, "that meat had to come all the way from Australia, Dad." He replies with a mostly unintelligible stream of speech, which I attempt to repeat with a question intonation at the end: "Are you sure it's not Kangaroo?" I interpret this as a joke and laugh lightly. Dad adds, "Joeys, they call them," which I don't understand at first until I ask for clarification and he repeats (**scaffolding**). We continue a discussion about whether or not Kangaroos are native only to Australia.

At 10:35, Dad reaches for his bag that he takes with him to the senior day care center everyday. Mom interprets this as a meaningful action and starts a conversation about looking for his birthday cards later (**EI-2**). We use scaffolding techniques to work our way through this conversation.

Mom, Charles and I carry on a conversation about our cats who are at home by themselves. Dad just continues eating until 15:15, when he announces that "he's finished." At 15:40, he reaches twice across the table in the direction of the salad dressing. He can't reach the dressing himself, yet Charles and I both understand that he wants some by interpreting his arm movement as meaningful (**EI-2**). At 15:55, Charles starts pouring dressing onto Dad's salad. He suggests that Dad should, "just say when," and as Mom and I are both also watching the pouring, I interject (after 5 seconds of pouring) "Dad, he said to say 'when'," while Mom interjects "when," speaking for Dad. Interestingly, Charles responds to the suggestions made by Mom and me

instead of waiting for Dad's instructions. After Charles has stopped pouring, Dad tries to make some commentary about the dressing, but it is not intelligible. I ask, "Dad, do you want more or not?" while Mom answers for him saying, "that's fine." At 16:10, at least ten seconds after Charles has stopped pouring the dressing, Dad yells out "when!" as a joke. He exhibits a huge smile and we all laugh (**life narrative**).

Mom tells a story about her father refusing to eat spinach when she was a child. My mother used this as an excuse not to eat her own spinach when she was young, but her mother stood up and forced her father to eat the greens as an example for the children.

At 21:15, I tell a story about Dad eating the gristle off my meat as a child and saying "that's why I have such beautiful skin." Dad listens to the story and declares, "nonsense," indicating that he doesn't remember these occurrences (**life narrative**).

At 24:00, I start a conversation that is based on Dad's orientation to a cat that he is petting on the floor to his left (**EI-1**). I say, "Is that Queenie, Dad?" Dad doesn't answer me, so after six seconds, Mom answers for him. At 24:10, Dad initiates his own topic of conversation about our trip to the vet that day. He is interested in knowing what the vets found in the cats' ears. Here it is as though he doesn't wish to respond to my empty nonsense conversation about Queenie, but instead directs the conversation about the cats to suit his own interests. I end up shutting down this conversation about the cats ears having ear mites, perhaps because my mother and I agreed earlier in the day not to discuss the trip to the vet with my father to avoid upsetting him. I make this decision based on our previous interactions where he has gotten upset about bad news concerning the cats (**life narrative**).

At 25:20, Dad reaches for his bag again and is visibly searching through both of his bags to find his cards. I see his actions, so I tell him (again) that Mom is going to look for the cards tomorrow (**EI-2**). This is also part of the previous **EI-2**, where Dad reached for the bag.

Charles and Mom and I begin the process of clearing the table while dad just sits there waiting for his dessert. At 33:05, I start a conversation about the winter Olympics, asking Mom if she has seen Apollo skate yet. She says she doesn't understand what's going on when she watches because she hasn't been following it closely. I drop the conversation, but at 33:20, Dad offers up information for me, "He hasn't raced yet," which I interpret as "he hasn't reached it" (I state this, with question intonation at the end (**scaffolding**)). Dad repeats himself twice. Mom starts vacuuming and the tape is unlistenable. Dad's dyskinesias are getting worse at this point. He ends up hanging his head down until his dessert is served to him at 38:30.

At 41:45, I ask about the new vacuum to which Dad replies (somewhat through mumbles, but I seem to understand anyway, based on our shared **life narrative**), that it's about 5 years old. I tell him that he is talking about the other vacuum since he can't even see what I'm talking about behind him.

At 43:00, I ask mom if it's possible to just take Dad to the center for a half day. Mom says it's ok. Only after we have settled this between us do I then ask Dad if he even wants to stay at home with Charles and me in the morning. Perhaps I know based on our **life narrative** that he would

always prefer not to go to the center if he can avoid it in any way. When I do ask, he says, “lovely.” I then announce that we’ll look for his birthday cards when we get there tomorrow. Mom and I then turn back to a discussion about their cats. At 46:05, I offer to take Dad into the other room to which he responds, “yes please.” The tape ends at 47:20 when I turn it off because the whole family has migrated into the TV room.

4.16.06 A

Recording first occurs at breakfast time. Andrew is playing music so it is too difficult to hear. Dad is only engaged every now and then; when he does talk, it’s mostly just a few words at once, not conversations. Andrew is whistling along to the music, there are kitchen noises like water running and dishes clanging. Dad just eats and listens to the music and then falls asleep after eating.

At Lunch, Charles has just shown up from a camping trip. Charles and I talk while Dad sleeps in his wheelchair at the table. When we finally turn our conversation to a famous British television series, Dad seems to be listening. Even though he has his head hanging down and appears to be asleep, at 58:40 I engage him in the conversation by talking about a character in a Fawlty Towers episode called “Communication Problems”. I do an imitation of this character’s part and Dad does one himself. This is an example of how we draw on our **life narrative**, where we rely on our shared experiences to build meaning. (58:40-1:01)

4.16.06 B

At the beginning of this tape, I move Dad into the music room to help him arrange his records back onto the shelves. I have first pushed him over to the area where the records are so he can see what needs arranging. Then, I reorient his wheelchair to the shelf so he can direct me where the records need to go. With a record in hand and leaning down to the bookshelf, at 00:14, I ask, “where?” He responds in a phonological stream that is almost completely uninterpretable, but at the same time, he is pointing very closely to a group of records among which he wants me to place the record in my hand. I can tell with relative accuracy where he is directing me because of how specifically he is pointing at this group of records (his hand is only inches away from the group of records). I am relying very heavily on **EI-1**, yet I still say, “what are you saying,” (00:24). Once I go ahead and place my hands on the records, further narrowing the field of semantic possibilities, he is able to say, “go left,” which I repeat with question intonation for clarification. As I page through the records, working my way left, he stops me by saying “there, there.” I place the record exactly where he has directed me (**EI-3**). I then move him back to a stack of CDs he is interested in arranging. At 1:30, I ask, “what are you doing now,” to which he responds by pointing straight ahead of him, indicating that he wants me to move him forward (**EI-1**). Instead of taking him over to get the CD he is pointing at, I go over and get it and bring it to him. I have been having a lot of trouble moving his wheelchair across the carpet, so I am likely trying to avoid having to move him.

At 1:33, Dad reaches for his music bag that he takes with him everyday to the senior day care center. I interpret this act as meaningful (**EI-2**) and say, “are you trying to get this stuff ready for tomorrow cause I think you’re staying home with me tomorrow.” I then have to adjust the

camera to capture out new semantic field that includes the stereo system and excludes the previously relevant bookshelf of records.

As I continue to put away his CDs, I ask him to approve of my actions as I go along. At 2:20, I say, “now where?” to ask what he wants me to do for him next. He says something along the lines of “there’s one that belongs xxxx” while pointing to the top of the stereo (**EI-1**). I think he is pointing to the record on top of the stereo, so I pick it up while repeating his statement, “the one that belongs=” with a pronounced hanging intonation at the end indicating that he can fill in the rest of the sentence. He tries to fill in the rest of my missing meaning, but the only word that sounds intelligible is “off”. He is, however, also pointing directly at the top of the record player to my right, (**EI-1**) so I appear to understand that he wants me to take the record off the player and put it in its sleeve. As I proceed with taking the record from the player and putting it in its sleeve, he makes a comment that is mostly undecipherable except for the word, “first”. From this one intelligible word and the context of my ongoing actions of putting away a record in its outer sleeve, I understand that he wants me to put the record in a paper sleeve before putting it away in the outer cardboard sleeve. I say, “in this?” as I pick up the paper sleeve to gain approval. After this process, I say, “now where? Now inside this?” as I pick up the outer sleeve and then ask if he wants me to put it on the shelf (**EI-3**). He responds by saying he’ll show me.

In order for Dad to show me where to put away this one record, I have to both reorient the video camera to include the shelves and then reorient him in his wheelchair to the shelf area. As we negotiate the proper location for the record, Dad says something along the lines of “xxxxthe way in,” which I interpret as “all the way in” (repeating it with a final question intonation). This **scaffold** indicates that he should restate his original utterance more clearly and he replies with “other way, the other way in.”

After putting this record away, I turn Dad back around and he points straight out in front of him, which I interpret as a display of his desire to get on the computer to look up his stock prices (**EI-2**). I offer, “you wanna do the Framlington?” (the name of his brokerage), and he approves of my offering with a “yes”. As I am moving him across the room toward the computer, I have to leave him for a few moments while I reposition the video camera. When I come back to him, he is displaying an interest (by pointing) in getting into the cabinet where I have left him (**EI-1**). I have to move parts of the sofa in order to get into the cabinet Dad wants access to.

At 6:00, Dad starts a conversation about his sister Philippa’s hip operation and his desire to call and check on her. In order to understand exactly what he is saying, I’m using **scaffolding** techniques (clarification requests, comprehension checks) quite extensively.

At 9:30 I initiate a conversation about Queenie and then put her on Dad’s lap for him to pet her. Dad attempts to comment on Queenie’s behaviour at 10:05. He repeats several different incarnations of “she flops around” (five times) while I say “what” or “she what” indicating a complete lack of understanding.

I turn Dad back around and move him back to the record player to put on some music (with the cat on his lap). I have to leave him to reorient the camera again. I ask what music he wants me to put on and then ask if he wants to stay in the music room or go into the kitchen. We have to

negotiate his response through scaffolding over the next 20 seconds. When I put the record on at 13:00, I seem to have difficulty getting it to the right place on the record. Dad helps me figure out how to place the needle by pointing to the stylus and indicating how I should move it (**EI-3**). Even though we have several more conversational exchanges about where he wants to be situated, the Shostakovich is so loud that from 14:00 on, no other conversation is intelligible until a quiet bit of the music at 15:15, when I bring him water and tell him Mom says he has to drink some. I turn off the camera at 17:06 due to the loud music (and the fact that I know Dad absolutely despises people talking while he is trying to listen to music).

5.24.06 A

This tape begins with Dad and Charles interacting in the music room as they look through his blue box of old documents and letters. Dad is directing Charles through pointing and speaking (**EI-1**) where to move other boxes to get at the blue box out. Charles finds Dad's scrapbook and Dad points to a picture of his old Austin Healey, which sounds pretty much unintelligible, yet Charles is able to agree that it is a beautiful car because they are using the picture to frame the referent (**EI-1**). At 4:00, Dad makes a comment about a football team, which is not readily decipherable. Charles doesn't understand and says, "pardon?" As Dad begins his repeat, Charles comes to look over his shoulder and once he sees the picture, he says, "whose football team?" Apparently they are looking at pictures of Dad's father's football team. Dad drops the album onto the floor at 4:25 and Charles rushes over to pick it up. Dad continues to show Charles specific pictures out of the album. Charles and I both use **scaffolding** techniques to understand what he is saying about a particular university in England that Simon Cowell (the host of American Idol) attended. Dad holds up the album for me to see pictures of the college (6:40) (**EI-1**).

When (7:05) Charles asks Dad if he wants to go into the living room to look through his papers in the recovered blue box, he says he wants to go pull the weeds on the walkway. Charles then launches into an explanation of all the outdoor chores he has already completed for Dad. Dad then asks if there's a chance he can also do the lawn, to which Charles responds that he was already planning on doing it. We continue a discussion about the yard work that still needs doing. Charles takes Dad to the living room (8:30).

At 9:18, Dad makes a joke about the camera. He says he probably won't say anything now that the camera's on. I have to use **scaffolding** techniques (clarification requests, comprehension checks) to understand his utterance.

Charles puts Dad's blue box on his lap and I offer to make him lunch but warn him about getting food all over the contents of the box. Dad explains to Charles what he is looking for in the box, but it is unclear whether Charles understands him or not (he just listens without any requests for repeats or clarification). When I ask for information about who put together the box (11:15), Dad has to repeat himself three times. The **scaffolding** process is clear here, as we eventually narrow down my understanding of his utterance to the last one missing word. Charles warns Dad that he is about to drop the box onto the floor and asks him if he wants to sit up a little bit.

At 11:45, Dad says there's a letter in the box from his boarding school saying he was in trouble for wetting the bed. Charles makes the decision to lean Dad's chair back and goes ahead and does it to avoid spillage of the box contents. Dad hands Charles a few letters (that he wrote as a child and sent home to his parents) to look at and makes a comment about how many students were at the school. Charles needs two repetitions to understand. Charles begins reading Dad's cricket statistics back to him from his letter while Dad listens (14:40).

At 16:15, I ask Dad what exactly Dad is looking for. He hands me Roy Heaton's passport and makes a comment about something Philippa needs as she stated in her email. At 17:30, Dad says something completely unintelligible. Both Charles and I use scaffolding techniques to figure out how his meaning is linked to our ongoing talk.

I bring Dad's lunch in for him to eat at 19:34 and as he tries to move the box off his lap onto the floor, he squeezes it too tight and he spills much of the contents. Charles comes to clean it up. At 20:40, I start to read one of Dad's letters where he asks his Mom and Dad to please buy him some caps for his cap gun. I am thoroughly amused by the letter. I sit on the ground and continue to read Dad's letters home to his family. When I don't understand what is going on from the letters, I stop and ask Dad for clarifications. Dad's letters talk about his bunk, his trunk, and his general set-up at school. He asks for his "sweet coupons" which he would like to sell to "an apparently willing buyer." I stop to warn him about his food falling off his lap at 25:00.

I continue going through Dad's letters and reading aloud the interesting bits. Dad only interjects short and direct comments when I ask him questions about the letters' contents. At about 43:50, Dad initiates a conversation topic. I don't appear to understand what he has said at all. After my first "what," he repeats and then I continue to use **scaffolding** techniques, repeating what I have understood and allowing him to just fill in the blanks.

At 44:30, I say "I can't understand you," which elicits a full repeat. At 45:00, I summarize his comments with a rising question intonation at the end to ensure that I have correctly understood (**scaffolding**). I then get up and announce that I am going outside, so I turn off the tape at 46:00.

5.24.06 B

Only the first two minutes of this tape have useable data. Dad is on his knees in the living room in front of the television trying to find a particular videotape to play. We have a conversational exchange in regard to this video at 00:16 and then again from 1:30-1:58. Dad is very frustrated by many things: he can't find the video, he can't get the TV to switch over to the correct setting and he can't explain to me what the problem is with the TV. He repeats himself several times, getting louder and angrier. I use **scaffolding** and Dad actually modifies his utterances to aid my understanding. Dad seems to be doing most of the work and I seem to be doing a relatively poor job of helping out. This is an instance where we are building meaning based on the objects in the room (the TV, the video, and Dad's orientation to these things) and based on our ongoing building of relevant utterances (**scaffolding**). Here we are also using **EI-1**.

7.04.06

This tape takes place at the kitchen table while we are eating breakfast. Mom serves Dad his bagel sandwich on a tray, but he sits and reads the newspaper that is spread out on the table

instead of picking up the bagel. Eventually, at 1:26, he tries to pick up his bagel, but the sandwich falls apart so he eats it in parts. Dad continues to struggle with his food while the rest of us sit down and start eating our own sandwiches. At 2:50, Mom serves orange juice and helps Dad with his sandwich, advising him to, “use [his] other hand.” At 3:29, he manages to get his orange juice to his mouth (in a real glass) all on his own. He continues to read the paper while he eats. For the most part, Dad feeds himself his sandwich.

At 9:32, I ask Dad if he had ‘sea legs’ or felt seasick at all on their cruise to Alaska. He starts telling me about the ship and the waves and we use **scaffolding**, including clarification requests and repetitions to negotiate meaning. We do the same negotiation techniques at 11:30 when Dad talks about the specifics of the North Pacific weather conditions. Mom also helps **scaffold** (repeating parts of what she understood from Dad’s speech) in order to aid my understanding. We continue talking about Alaska and Dad is fully engaged in the conversation, but we have to negotiate meaning together as we can’t understand him the first times he says a novel utterance. At 15:55, we rely heavily on **scaffolding** techniques to understand what he is saying. Interestingly, I can’t understand Dad at all, but it seems as though as Mom is able to repeat and paraphrase for him, that her having been present at the event he is trying to describe allows her to catch more of his meaning. She seems to know what he is saying because she has access to the context of the event being described (**life narrative**).

At 19:00, I ask Dad what his favorite part of the cruise was and he says it was the workshops. Mom expands on what Dad is describing about the workshops to help me make better sense of what he is saying. Mom translates for him at 20:40 and I continue to scaffold off the meaning that I did understand, allowing him to fill in the blanks.

We turn the conversation to talking about upcoming weddings and my parents’ church. Dad seems to be listening and gives some minor backchannel cues, but doesn’t participate in the conversation overtly.

At 30:37, Dad starts a conversation about how his cat always lays right at the base of the wheels of his wheelchair and then he can’t move. Here he is looking down at the cat while he is talking, so my understanding is aided by **EI-1**. We then have a discussion about Dad’s doctor’s appointment the next week.

At 32:40, Dad asks for more coffee and we have a discussion about it. Dad and Charles have a discussion about Whiskey where Charles requests several repeats from Dad. After pouring Dad’s coffee, he tells me he “prefers it in another cup,” and so I go to pour it into his preferred cup for him. My understanding here is aided by Dad’s orientation to the cup and his gaze toward it (**EI-1**). Charles and Dad sit together reading different parts of the newspaper in silence at the table. After a few minutes, Dad seems to fall asleep in his chair, so Charles gets up to turn the camera off.

7.05.06

Charles and Dad are having a conversation about ipods at the kitchen table from 00:00-7:50, when the food is served and they start eating instead of talking. This conversation is facilitated by calling upon our **life narrative**, because Charles has had many past conversations with Dad

over the preceding months. By the time of this conversation occurs, Charles already has an understanding of Dad's interests and concerns about getting an ipod and transferring his music collection to the device. As they call upon these past conversations, Charles uses **scaffolding** to build links between ongoing utterances.

At 15:05, Dad initiates a very short utterance about his Aunt Olive in England. The sounds are mostly unintelligible, but we understand him thanks to our shared **life narrative**. Others outside of our family would likely relate the intelligible word, "olive" to the edible fruit, rather than to a family member.

At 18:20 Dad utters something about my cell phone ringing while I was outside. He directs his gaze to the telephone (**EI-1**) in my hand and I use **scaffolds** between utterances to understand his meaning.

A 19:00, Charles and I are taking Dad swimming in the pool. While there is not a great deal of audible talking due to the camera's distant placement and the fact that we are moving between ends of the pool, the conversations that do occur are all short utterances related to the instrumental needs such as taking a rest or going to the side. **EI-1** is most relevant here.

7.26.06

This tape is a recording of Dad and me getting online to order some CDs for him. At the beginning, we Charles and Dad are trying to figure out whether or not the computer is online. At 1:48, Dad makes some commentary I don't understand, so I use **scaffolding** techniques to negotiate his meaning. At 2:30, Dad makes a joke about the cat only having 8 lives left (the cat is perched on the top of all the stacked up sofa cushions and looks poised to fall – **EI-1**). He has to repeat the joke twice for me to be able to understand him. I finally do understand thanks to our shared **life narrative** that allows me to be familiar with Dad's sense of humor.

At 3:32, Dad makes a comment about mites around the cat's eyes, after which I use a partial repeat and clarification request in order to elicit a repeat (**scaffolding**). We get into a debate about whether or not he's seeing mites or fleas(**EI-1** is also relevant, as he is looking at the cats' eyes). He says he saw little moving black things last night and this morning. Our debate about the presence of the fleas also relies on our shared **life narrative**.

At 5:10, Dad uses pointing to direct me to a box of CDs so that I can know how to spell the comedians' names as I search for them online (**EI-1**). Dad seems to be having trouble getting enough air behind his words, so I am using quite a lot of scaffolding and repeats of what I do understand to capture his full meaning. At 6:16, Dad starts singing one of the pieces of classical music that the musical comedians Flanders & Swann have turned into a parody. I seem to be having trouble finding these comedians in my search so Dad suggests that I use a broader category. At 7:55, I start whistling and then singing the *Go Get the Telephone* parody of Flanders & Swann. Dad joins in with me in the singing. This is a bit from Flanders & Swann that Dad played for me frequently throughout my life. What is most interesting here is that I don't actually say any metacommentary on the piece, but rather, we just start in singing together without any prior coordination. The intersubjectively shared humor here is based on our **life narrative**. Dad takes up the singing himself and is trying very hard not to let his singing

completely devolve into a laughing fit. We continue taking turns singing back and forth until I find what I've been looking for at 8:20.

At 11:20, Dad asks me to look up Gergiev; actually, Gergiev conducting Prokofiev. We talk about Prokofiev's *Romeo and Juliet*. As I read out the Gergiev works I've found Dad says that he's "got that," to everything I read that is available through Amazon.com. At 14:50, Dad lets me know that he wants me to narrow it to piano concertos. He continues to reject everything I read out, as though he can't remember what he's looking for and is waiting for me to read out the correct name in order to recall it for him. At 15:55, Dad says, "Ashkenazy," so I type in his name in conjunction with Prokofiev and begin reading out the list of search results. At 17:30, Dad starts talking about Ashkenazy's conducting and even though I ask for clarification, I don't seem to ever understand what he says. He then asks me to look for the DVD. At 18:20, He has me look up Carl Nielsen. He attempts to correct my spelling several times and my tone of response seems to be one of annoyance when I insist I've spelled it correctly. At 19:00, I ask him why he keeps talking about getting DVDs instead of CDs and he insists that he wants the picture. Dad then directs me to start searching for Berlioz conducted by Colin Davis. Again, as I read out the search results, he rejects everything. I then suggest, "are you sure Amazon is the best place to buy these?" to which he doesn't really respond (21:06). At 22:00, I again say "I don't know if Amazon .com is the best place to look for these things," and then suggest that there are probably better search engines. Dad quickly says, "They're all new," in reference to the CDs he's looking for. When, at 22:18 I ask why he can't go to Gramophone to buy them, he lifts his head and brings the Gramophone magazine out of his lap and puts the front cover directly in front of my face in what appears to be a forceful or indignant display that he *is* already looking at these in the Gramophone (**EI-2**) Directly after this, I seem annoyed and specify my suggestion further with a raised tone of voice when I say, "Can you buy them through a Gramophone website?" Dad then says, "no," and goes into a long explanation that I don't understand. After I say "what," he continues to explain that it he can't get them because they're imports. Throughout this entire interaction, we are relying on **EI-3** to make meaning, as Dad is directing the relationship of my fingers to the computer keyboard, in a way vicariously typing himself instead of simply giving me the Gramophone magazine.

At 23:01, Dad says the names, "Beecham" and "Mozart". After I clarify the spelling of "Beecham," I go to type it in. I read out the search results and Dad points to the entries he's interested in (**EI-1**). During this entire interaction, it seems like if we didn't have the Gramophone magazine, the computer, and my background knowledge on classical music (**life narrative**) as social and environmental contexts, his phonological streams would be very difficult to understand. He seems to be mumbling and speaking very quietly throughout this tape.

At 28:18, I ask Dad if there's anything else he wants me to look up. He stutters his way through his pronunciation of Mozart and then starts spelling "Barenboim", which I have quite a lot of difficulty understanding. I mess up both my pronunciation and spelling of this name because it is new to me. As I read out these search results, Dad says "no, no, no," to everything. At 29:55, Dad says, "this is the one," as he starts giving me the magazine and pointing to the advertisement for the CD (**EI-1**). This is the first time he has actually allowed me to look at the magazine directly instead of just waiting for his oral directions. I ask why he doesn't just order straight from the label and he informs me that you can't do that. I come to the conclusion that he's too

early – that the recordings are obscure and have just barely been released. I then suggest getting the guy at Horizon records to order these for him since we are having such difficulty finding them. I can't understand his response at all even after asking him to repeat. I finally find the specific Barenboim work he is looking for at 32:10 and tell Dad it costs \$25. He lets me add it to the shopping cart at 32:10.

At 36:00, Dad has me look up "Herz," which he has to spell for me (**EI-3**). As the name doesn't come up, I tell him he has to give me a first name too, which he spells out for me. I still can't find this artist. I start packing my things while I let Dad peruse the magazine and look for other CDs he wants me to look up.

At 43:20, I come back and ask if he's found something else to look up. He mumbles something and then says a name I don't know or understand. He then spells it for me and I still repeat it with a question intonation at the end to clarify. As I read out the findings, he tries to follow along on the computer screen. I narrow the search to Byondi and Mozart but this still doesn't result in the CD he is looking for.

At 46:10, Dad tries to tell me something about Ashkenazy. I ask, "Did you say Ashkenazy?" He then starts to comment on a mis-spelling of his name, saying something about "Z-E," not "Z-Y." He then says that he died recently, but I don't understand him (in the moment) at all. I ask him to spell out what he's trying to say and as he spells out "D-I-E-D," it appears that I hear, "D-I-N-D," which I seem to think is someone's name rather than understanding that Ashkenazy just died recently. As Dad tries to get me to understand by repeatedly spelling out "D-I-E-D," I continue to misunderstand him. I even go so far as to turn to the computer and type in "D-I-E-D," still thinking it is someone's name. Once Dad sees what I'm doing (47:05), he sighs and says, "Oh God, no" and it's then that I realize what he's been saying all along. I finally understand completely at 47:40, a minute and a half after he started this conversational thread.

From 47:00 to 56:00 I take a phone call with Sasha while Dad just sits and waits.

At 59:00, Dad mumbles a sentence twice. I then say that I can't understand a word he's saying, which is a metadiscursive commentary that again engenders a full repeat, which he speaks somewhat more clearly. This serves as a **scaffold** on which Dad can build his next turn.

8.26.06

For most of this breakfast meal, the family is discussing issues that don't really concern Dad, so he is unsurprisingly quiet.

Then, from 39:02- 46:55 Dad talks about how he doesn't have feeling in his fingers. Mom begins the conversation by asking about a lump Dad says he felt on the cat's back, but Dad tries to explain that the lump may not really exist; it may be because of his nerve endings in his own fingers that he feels strange things that aren't actually there. This conversation relies on co-building a context for his utterances based on the gestures he is making with his hands and based on scaffolding techniques used by Charles, Mom and myself. This is a good example of **EI-1** and **scaffolding** working together.

10.12.06 A

I feed Dad his meal in the living room. His mouth is full for most of the time, so there is not much conversation. We only speak small practical snippets back and forth about feeding him. He then slides down in his chair and falls asleep.

At 33:20, I move Dad into the music room to put his cassette tapes away. This interaction continues until 46:00. Every utterance here is embedded in Dad's reference to physical space and objects in the immediate environment. He is seated in his wheelchair facing the cassettes on a bookshelf while I am partly oriented toward him and partly toward the bookshelf. He directs my attention toward the particular drawers of cassettes through pointing. Interestingly, I don't have to ask him to repeat often because his pointing and glance are so effective in guiding me to his appropriate meaning. This is an interaction that relies mostly on **EI-1** to create intersubjective understanding.

At 42:30, Dad asks me to put away a record by the British composer Simpson. I make a joke that is a reference to a Monty Python audiocassette tape Dad use to play all the time: (from the string salesman skit) "Simpson....Simpson....Simpson – French, is it?" Dad laughs heartily in return. Although this imitation I do is very short, we laugh together because we have a shared context of jokes and humor built up over a lifetime of being in the same family. Here, this is a clear case of how our shared **life narrative** aids our understanding.

From 47:20-49:00, we move back to the living room again and carry on a conversation, but the opera Dad is playing on the TV is too loud to understand much from the videotape.

At 54:00, we have a short conversation about batteries where I understand what he wants without repetition.

10.12.06 B

Dad feeds himself Indian food while watching opera on the TV. There is not much conversation at all. Then, I talk to him while I'm preparing to go out to the store. I am setting him up for my leaving by laying out his medicines, water bottle, phone, etc. I ask him if he wants me to leave the opera on even though he won't be able to switch it to TV after it's done. He says that's fine. As I am the one initiating most of this conversation, he just nods or says one or two words in agreement or understanding.

At 11:15 Dad makes a joke about the learning to play the guitar, which I can understand as humorous because of our shared life narrative.

10.25.06

Dad initiates a conversation with Charles at the beginning of this tape. Dad is already seated at the dinner table while the rest of us (Mom, Charles, and I) are getting ourselves and the food to the table. Dad asks Charles about his day. For the first couple minutes, I am trying to place the camera in a new position, at the top of the cabinets, to rectify the problems I've been having with previous films (such as not being able to see all of us).

We talk about the trip Dad and I took to Clemson to meet up with Doug Kleiber. At 3:03, I tell Dad that he's eating a Waldorf Salad, which is a joke based on our collective **life narrative** and family sense of humor that has been cultivated through John Cleese's Fawlty Towers. I am alluding to one of the episodes where a child has a fit about a Waldorf Salad, which Dad has always found hilarious.

Dad is quiet as he is focusing on eating his meal. At 4:25, Mom and I make suggestions to him about how to eat his food, which he completely ignores.

At 7:03, I try to bring Dad into the conversation by specifically addressing him when I say, "Dad, what is Jericho about," asking him to explain a TV show he likes. As he tries to answer, most of what he is saying is unintelligible and Mom pre-empts his speech by explaining it herself. She is only able to do this because she knows what types of things Dad might have to say here based on their shared **life narrative**. After Mom's summary, I ask a question, but direct it to Dad, which he responds to with a simple, "mmm."

Mom and I primarily talk about the dogs, coyote sounds and a story Mom heard on NPR about a dog who licks psychedelic substances off of frogs.

At 15:50, Mom starts feeding Dad his salad even though he's still feeding himself his beef stew.

At 26:00, Mom asks Dad if he's alright and he responds only with a nod. At 26:56, Dad looks at the clock and asks what time Jericho is on. His gaze toward the clock (**EI-1**) and our shared **life narrative** about the TV shows Dad likes to watch help us to understand what he is asking here. As Dad wipes up the table from his meal, he makes a joke that is mostly unintelligible, but I understand the gist, which is that there's "only about 27 minute of film in an hour" during any given Jericho episode. I repeat the joke so that Charles can understand. At 28:18, I say we have to get Dad into the living room for his show and Charles moves him from the kitchen table while singing the Bob Marley song about the "Walls of Jericho."

11.07.06

I am making and serving dinner. At 3:30, I try to interact with Dad, but his mouth is full, so he responds with a simple, "mmm" to demonstrate agreement. He makes a short comment about the food at 5:20.

At 5:56, Mom elicits Dad's help in her telling of a classic family story about our trip to Wales about 25 years ago. Dad doesn't even answer. At 6:40, he does participate minimally by contributing the name of the host at the Bed and Breakfast. Mom continues telling the story of having a fancy dress dinner where I came down in my nightgown. Mom goes on to explain to Charles about our family's last trip to England with Dad. Dad doesn't participate in the discussion even though we're talking about subjects that normally interest him.

11.08.06 A

This entire tape is Dad dictating his Christmas letter to me. He starts out the letter talking about his hallucination episode that led him on a path of destruction through the house. He describes how my mother found him and took him to the hospital where he fell in and out of consciousness

for four weeks. While we are working together to write this letter, I am relying on my own knowledge of the events that took place and my life's store of knowledge of how he usually tends to write his Christmas letter (our shared **life narrative**). I often use **scaffolding** techniques throughout to allow Dad to repeat just small parts of his utterances. The physical act of writing a letter and all the body positionings that accompany this task also serve as important contextual clues to aid our understanding. For example, he often nods his head toward the computer screen or keyboard, which in combination with his sounds, allows me to know he wants me to change something technical about the typing process. This tape includes excellent examples of how **EI-1**, **EI-3**, **scaffolding** and **our shared life narrative** work together with Dad's verbalizations to create meaning.

11.08.06 B

I am helping to put Dad's audiocassettes back in order in the music room again from 00:00-10:40. We are using both **EI-1** and our shared **life narrative** to aid our understanding, as he is pointing to places or particular pieces of music and as I am already familiar with many of the names of composers and also his system of arranging cassettes.

I take a call on my cell phone while Dad continues to arrange his cassettes.

At 24:55, there is some good data, but our conversation is very brief and the music is so loud it's difficult to hear the speech clearly.

At 29:40, I begin moving Dad out of the music room and wheeling him into the living room. We have a discussion about a cassette tape that Dad has been trying to fix. Somehow, the tape has come unraveled and he has been trying to wind it back in himself. We have a friendly argument about letting me fix the tape rather than him trying to continue doing it, as I think he is actually unwinding it more by accident. During this conversation, I truly cannot understand what he is saying, even though I have the **EI-1** contextual cues (the tape in my hand). I don't know how to arrive at his intended meaning and I finally just say, "I can't understand you."

From 35:36-36:52, Dad and I have a conversation in the living room that starts with a discussion of the free CDs that come in a sleeve inside his Gramophone music magazine. Here, we are relying on the **EI-1** to aid our understanding.

Then, from 37:10-38:27, the conversation moves seamlessly into a conversation about my car that is in for repair at the mechanics'. We have several conversational volleys where I rely very heavily on **scaffolding**, trying to elicit repeat statements from Dad. We seem to have a misunderstanding about whether Dad is talking about mom coming home at five o'clock or the auto repair shop closing at five o'clock..

At 39:50, I realize that in my short absence, Dad has wheeled himself back into the living room and brought the unwound cassette tape into the living room to try to fix it again. As I hold the cassette up, it is clear that he has exacerbated the problem. My mother generally also has a rule that he should not try to go from room to room on his own while no one is home because he often runs into things and breaks them or tries to get out of his wheelchair to do a task and then he ends up hurting himself. While I am taking on a tone of scolding for his messing with the tape

I've already said I would fix, he is begging me to "keep quiet!" so that Mom doesn't find out about his illicit odyssey. Because of my knowledge of the family rules and the physical presence of the videotape, we are relying on both the **EI-1** and our shared life narrative here.

11.08.06 C

We are at dinner and Mom is cutting up Dad's food for him. At 3:40, Dad makes a gesture with his hand that moves from the sauce on the table back to his plate, while he is looking at me. I interpret this to mean that he wants me to pour some sauce on his food, which I do (**EI-2**). He makes a short commentary about the food (which I have elicited) at 4:50.

At 5:15, Mom brings up the topic of Dad's day, which was spent with his fellow retirees from the office. Even though Mom is trying to elicit conversation from him, he only answers with very short utterances or simply 'yes' or 'no'.

At 14:48, no one is left at the dinner table but Mom and Dad. Dad actually initiates a conversation simply by pointing to the rose in a vase in the middle of the table (**EI-2**). (This is very similar to his gesture on 2.11.05 when he reaches for his bag and this begins a whole conversation about his missing birthday cards). While Dad is pointing to the flower, he simply says, "nice". Mom says, "what, honey?" and then he repeats himself. This simple gesture leads to an entire conversation about when the rose was cut and how beautiful it is.

At 20:25, I ask him if he wants some candy to which he responds simply, "mmm". We then have a short conversation about chocolate where he is giving simple one or two-word answers to my questions.

There is some interaction again at 28:40, but it is mostly inaudible.

11.23.06

The family is having a hodge-podge breakfast the day before Thanksgiving. My brother, Andrew is home with his girlfriend, Karolyn and they are gathered at the table along with Charles, Dad, and me.

At 4:40, Dad gives a mostly unintelligible answer to my question about whether or not he wants to go outside while we work all day. At 5:21, he talks again, but I can't really tell what he's saying. Finally at 6:00, he says that he'll just 'fit in with everybody else', meaning that he'll just go along with what everyone else is doing. It is not clear to me if we called on any additional contexts to understand this phrasing, as his words came out relatively clearly by this point anyway.

I end up feeding him for most of the rest of the time while all the young folks (i.e. everyone but my father) carry on conversations about music and about pig farms and an experimental dog farm at Karolyn's pharmaceutical company where the dogs are used to test new veterinary medicines.

At 26:16, Dad asks a question that seems completely out of context. I can't understand most of what he is saying, so I try to piece together his meaning using **scaffolding** and references to

previous utterances. I finally figure out that he is asking about “the town that is further east from Simpsonville.” Then, at 29:23, Dad mentions that there is soon to be a large bison farm out East of Simpsonville, which interestingly does have a previous relation to earlier discussions of animal farms. It is as if he didn’t think to mention this until we’d gone onto new topics. Then, not understanding how his sounds and his question were actually related, I provided very poor scaffolds. It is also interesting that ‘poor’ scaffolds (ones where I’ve got the wrong idea/line of thought) actually work to help us get to a common understanding anyway.

At 31:30, Mom starts another conversation about going outside to work on the pool, but it is almost inaudible with the TV playing and other conversations going on at the same time.

At 32:40, Dad is trying to speak to me but I say, “I’m sorry Dad, I can’t understand you”. Mom says she’ll read his lips and asks him to turn his head toward her. She adds, “look at me.” Here, she would be relying on **EI-1**, making meaning by looking at another “object” (Dad’s lips) in her surrounds.

At 34:00, there is the sound of birds chirping on the TV, loudly (as in a commercial) and repeatedly. Dad says, “A bird thinks it’s spring,” five times, eventually yelling at the end. Although Mom eventually gets his meaning, as demonstrated by her repetition of what he’s said, we still didn’t really get what his comment was in reference to. In essence, we didn’t really get his meaning. We got the utterance, but didn’t know its significance. It seems that what is happening here is that we are trying to rely on **EI-1** in order to make sense of what Dad is saying, but we are not able to pin Dad’s words to the correct environmental referent.

I move Dad and the video camera outside and then at 46:18, Dad starts a conversation by stating, “Amy we need the nails”, which is only intelligible because I know we need nails based on having done this same chore dozens of times over many years and because we are physically situated in the space where we are about to do the chore (**EI-1** and **life narrative**). Dad directs me as to whether or not I’ve collected the right screws and then points to tell me where I need to put the screws.

At 50:05, Dad starts a conversation with Andrew about a music CD Andrew made for him. Andrew responds with only one “what” before he figures out what Dad is talking about. Dad and Andrew only ever really talk about music or chores that need doing, so Andrew can probably safely embed most of Dad’s utterances in music contexts and figure out what Dad means. They are having this conversation while they are outside by the pool, so the context of relevance is not the physical environment, but more their shared **life narrative** about music.

11.24.06

This tape takes place around the table on the morning after Thanksgiving. Charles, Karolyn, Mom and I are all present and the initial conversation is about Dad paying us for the chores we’ve done for him in the yard since we’ve been home.

At 1:28, Dad is obviously looking at the sports page in the paper when he starts a conversation with Charles about Virginia Tech beating Miami and although his phonological stream is not readily completely intelligible, it appears that Charles understands him. His understanding is

likely due to using **EI-1**, whereby Dad orients himself to the newspaper while speaking. He makes a joke and then laughs, but Charles does not appear to understand him. Dad and Charles continue to read the paper while Mom and I talk about the dogs.

At 4:47, I ask Dad if he wants to go sit on Woodruff Road, a horrendous traffic nightmare of a place while Mom and I shop. This is intended as a joke and Dad's response is almost entirely unintelligible. Dad then says something about batteries and Radio Shack. I need several repeats to understand what he is saying (I use **scaffolding**).

As Dad continues to read the paper, he appears to get tired and puts his head down on the table to rest.

At 9:38, Mom starts telling Carolyn that "Peter woke up mean as a snake because he didn't get any food yesterday," (referring to the previous day's Thanksgiving meal). I embellish the ongoing joke by announcing that Dad thought the only thing that was on his plate was kale. Dad then adds in that there was just a little bit of white meat turkey. We are all laughing at my Dad's unfortunate situation of having to eat mostly vegetables during Thanksgiving meal. Mom summarizes Dad's comments to her upon waking about the Thanksgiving meal by saying that, "Amy was apparently very very sparse with what she put on his plate." I defend myself by telling Dad he could have asked for seconds of anything. He responds by saying that he did have seconds but that there wasn't room for much since all he had on the plate was kale. At 10:36, Mom comes over to ask him what type of bagel he wants. He says it doesn't matter but that he's very hungry. At this point, I chime in sarcastically, "Do you want some turkey now then?" to which he responds, "yes." Mom then teasingly tells me to warm him up some Kale and Dad says he doesn't ever want that again. Carolyn and I are giggling the whole time. I then started a conversation about Dad's complaints about the wine from Thanksgiving dinner. Dad says he doesn't know how anyone could market something like that and then I tell Carolyn that after Dad had finished "going off" about the kale this morning, he said (doing an impression of Dad), "That wine tasted like vomit!!" Carolyn giggles and agrees about the wine. This entire interaction is based on my family's understanding of a commonly shared sense of humor (our **life narrative**).

Andrew comes into the kitchen at about 13:00. At 13:45, Andrew asks Mom how she is this morning and Mom starts relating the joke about the Thanksgiving deprivation Dad underwent saying, "Dad's starving this morning because all you all gave him yesterday was kale." At 13:50, Dad starts concertedly interrupting Mom's storytelling, in an angry tone. At 14:07, I provide a **scaffold** for him to build upon as I summarize his commentary saying, "stop using the story for your own purposes?" Dad corrects: "Stop manipulating the story for your own purposes." I assure him that it's a joke and no one makes any further comments. During this interaction, we are trying to tap into our **life narrative** that indexes our rough joking with each other, yet Dad seems to think we are taking greater liberties than we should be allowed.

At 16:30, Dad knocks his cup of coffee onto the ground exclaiming, "Oh Damn!" Carolyn and I move in to clean up the mess. At 17:10, Dad pays Andrew for his outside chores. At 17:20, Dad starts telling Andrew something novel that seems not to relate to the ongoing discussions or the physical environment. Interestingly, Andrew puts his head in his hand and looks directly and

pointedly at Dad, which in itself seems to serve as a **scaffold**. It seems as though from Andrew's face, Dad can see that Andrew hasn't understood, so he repeats himself. I try to help out by scaffolding uttering the part of the sentence that I understood). After the scaffold, Andrew figures out that Dad is talking about a CD Andrew gave him.

Around 20:00, Mom asks Dad where he wants to go shopping today (this is a joke, based on the fact that this is the day after Thanksgiving and my family would never go shopping on this day). I answer for him saying, "he wants to go to Radio Shack." Mom says that's too simple, we should go somewhere more difficult to get to. Dad then suggests that we could go spend three hours in "Bedrooms, Baths and Beyond and two hours in Pier Imports" I correct his slightly mistaken names of the stores and Dad laughs. This interchange is also part of our ongoing **life narrative** about all the places Dad hates to go shopping. Mom then suggests that we can go to the bookstore.

At 21:18, I say, "Dad all next week on Channel 7 News they're following around this cop who goes after people who aren't handicapped who're parking in handicapped spaces." I explain that in the previews I've seen on TV, they're all people like me carrying like 6 bags from the store who say they just left their tag at home. Mom and Dad join into a discussion about the laws of handicapped tags. Mom explains that you have to pay extra to actually get the handicapped sign on our license plate instead of as a hangtag. I tell the story of a woman ranting and raving at the drug store because she claims two older ladies accidentally hit her car. The ranting woman was illegally parked in handicapped when the ladies apparently hit them. I go through the whole story of how Dad and I had to park in a different parking lot and walk over to the drug store because of the ranting woman until 27:25. Dad was present for this whole problem at the drug store, but he lets me tell the story and doesn't add anything at all. It's interesting to me that I started this conversation thinking it would be interesting to Dad and that he might have something to say on the matter, but he doesn't appear interested at all.

At 29:10, Mom starts talking about how she'd had to wake Dad because he wasn't breathing in the night.

Interestingly, at 30:10, Dad says there's a lot of "empty car... um.....cripples" During his long pause, he is looking at Mom as though he is asking her to help him find the words he wants. I fill in, "Oh, empty handicapped spaces." Dad finally finds something to contribute to our previous conversation.

At 33:30, Dad tells me to put the rubber handgrip back around his coffee mug, which I seem to understand because he is fiddling with the mug and gazing intently at it (**EI-1**). Even though I try to debate him, he insists that he wants it back on.

At 35:40, Dad asks Andrew where he's going to, to which Andrew responds with, "what?" Dad repeats and Andrew comes over to the table to tell Dad the plans for his band's tour. At 37:20, Dad tries to ask Andrew how popular they are in Charleston and Mom uses several scaffolds to aid Andrew's understanding.

We all then get up from the table and start helping Andrew and Karolyn pack their coolers of food so they can leave. Dad sits at the table by himself while he finishes his coffee. At 45:15, Andrew asks Dad if he can borrow a vice grip to fix his car. Dad agrees.

At 48:38, Andrew comes to talk to Dad about an automotive repair show he watched where the man finished working on the car and then later realized he had a piston in his pocket when driving around. Dad laughs. Karolyn and Andrew hug Dad goodbye. Right when they are already ready to step out the door, Dad calls them back to ask if they go by the way of Macon. Once he hears they're gone, he calls me over to get me to glue the rubber grip back onto his cup.

At 52:40, I ask Dad again where he wants to go shopping and then ask if he wants to go out to get a wig. This is an attempt to access our **life narrative** about joking with each other. Dad mumbles a response. When I ask Charles what he wants to do for the day, he says he'll consult the horoscopes. After he reads our horoscopes outloud, Dad initiates a conversation. The timing would indicate that he is talking about our present conversation topic, but he seems to be talking about insurance companies. I have to use many different **scaffolds** in order to co-construct meaning with him, as he's talking about car insurance companies calling their clients to tell them they should cut back to just liability insurance (a complex and context-removed topic). What does serve as a context is my previous experience with Dad when he had me call his car insurance company to see if he could start paying only liability. I rely on our ongoing **life narrative** and multiple **scaffolds** in order to understand him. This is the last conversation on the tape where Dad is involved.

11.25.06

This tape takes place during breakfast two days after Thanksgiving. Mom is making eggs while Charles, Dad, and I drink our coffee at the table. At 1:12, Dad initiates a conversation with Charles, but Charles appears not to understand anything. He says "what" three times as Dad continues to repeat. Eventually Charles understands, "we'll never get into Death Valley," which he repeats outloud as a comprehension check. Charles and Dad then continue their conversation about football. As they have now established the topic of football, they do not require scaffolds or comprehension checks as Dad mentions different teams and games.

At 4:15, Dad reproaches me for laughing at missionaries that were taken hostage and then quickly released. I explain that I think it's funny because I can't stand what missionaries do and that they are released with absolutely no harm done, but Dad says it's not something to laugh at. The three of us sit and read different parts of the paper together until I get up to help Mom make breakfast.

At 8:00, Dad starts reading out some of the upcoming games and times from the paper and Charles responds while Mom and I ignore him. When I bring Dad his breakfast tray around 13:05, he is having trouble managing the newspaper. It appears that he is trying to fold it. I ask, "What do you want done with this?" and he tells me to "leave it," while Mom tells me to "fold it up please." I hold the outer paper while Dad puts the inside leaf back in how he wants it. Dad takes a few bites of breakfast, some of which I feed to him and at 19:00, he opens a new section of paper and places it over his meal. At 19:26, I suggest, "Dad, why don't you put that away so you can eat?" Eventually at 20:30, he puts this section of paper to the side on a chair. At 21:00,

he reaches for it again and opens it up. I ask, “Are you trying to lay that down?” and then move his tray out of the way so he can lay out the paper again. During this interaction, we rely on the presence of the newspaper (an object in the surrounds) to anchor the meanings in our talk (**EI-1**). Dad manages to feed himself from his estranged tray while also reading the newspaper he has laid out on the table. Mom comes to sit down and she and I carry on conversations together. As Charles comes to pick up Dad’s tray at 38:29, Dad opposes his action with a grunt and grabs for the last bit of bagel on his plate (**E-1** or **EI-2**, depending on whether I consider a grunt to be “talk”).

At 55:10, I ask Dad if he’s done and if he wants to go to the other room and he says “No, I want to go to Green’s”. He wants to go take back the bad bottle of wine from Thanksgiving and is disappointed to find out Mom went ahead and poured the bottle out. I wheel him into the living room.

2.09.07

This film takes place in the kitchen when Dad is on the phone with his sister, Philippa who lives in England. I decided to tape this conversation when I heard the difficulties they were having. I counted Dad repeating a simple sentence to her (louder and louder and with much frustration) nine times and then ran to get my video camera set up. Obviously, the tape only recorded his side of the conversation. At first, Dad is listening quite a lot and just giving one-word responses or backchannel cues. At 1:25, he starts making more complex commentaries, but his dyskinesias are so bad that the talking end of the phone receiver is hovering (quite literally) over his eye socket, pushing up his glasses instead of being poised over his mouth. At 2:37, I try to reposition the receiver, but it moves right back afterwards. He says “bye-bye” at 3:20 and then Mom picks up in the other room while Dad remains on the line. At 3:53, Mom tells Philippa that Dad is upset with her (Mom) for not doing anything for Philippa for her birthday. She says that this has been weighing heavily on his mind and even waking her in the night to remind her. Interestingly, Mom then warns Philippa Dad is still on the line to “keep them straight.”

I remember Dad’s interaction during this phone conversation being much more interesting, but I seem to have started the tape too late to capture the bulk of the conversation. They both hang up at 7:55. I untangle the phone cord from Dad’s wheelchair and ask him if he’s already eaten breakfast and if he wants to go in the other room. I move him to the other room on his request.

3.13.07 A

At the beginning of this tape, Charles and I are helping Dad to sort through a large box of his classical music tapes. At 00:15, Dad is pointing to the cover of a cassette box and saying something that is mostly unintelligible. Charles, however, seems to have no problems understanding what Dad wants him to read out because Dad is pointing to a specific line on the cover (**EI-1**). At 1:58, dad reaches across the table and says something about “tha box,” that he is reaching toward. Charles is again able to understand and answer him based on Dad’s orientation in space toward the object (**EI-1**).

At 2:15, Dad initiates a conversation where he is not oriented to the box of cassettes but is instead turning to look in my direction. I don’t understand anything except the first word of his utterance and I use scaffolding to allow him to repeat the part I haven’t gotten yet. Once he

repeats, I understand. At 2:47, the same type of interaction repeats. At 3:23, Dad asks me to do something that I don't immediately understand but I orient myself to the wheelchair as he is leaning down and falling forward while indicating with his head that I should do something to the chair. The word, "move" is directly recoverable and I think because he is already falling down that he wants me to move him upright in his chair (**EI-1**). I am not quite accurate, though, and Dad asks me more specifically to move him into the other room (his eyes and head are no longer looking down at the wheelchair, but instead, he uses his head to gesture at the room behind us).

As I am wheeling Dad out of the room, he commands me not to go through the tapes and put them together myself. We have a contentious exchange of words about why I can't go ahead and match the tapes with their appropriate boxes myself (4:05).

When the tape re-starts, it is the next morning and all the cassettes and their boxes are strewn about the kitchen table. Dad seems to be completely frozen at the table, stiff and staring straight in front of him with his mouth gaping open. Mom and I interpret this facial expression as meaningful (**EI-2**). We both ask him if he's ok and he says, "yeah." I suggest that his medicine hasn't come on yet. I am trying to arrange the cassettes on my own while he continues to sit completely stiff with his mouth hanging open. At 7:00, he attempts to talk about where to put the tapes and is struggling against spit he seems unable to swallow and a mouth that doesn't seem to be able to move to his will at all. I use **scaffolding** to figure out the specifics of his meaning.

At 8:15, Dad sees that I'm starting to arrange the boxes of CDs and tapes into the large storage box on my own. He aggressively says, "don't do it now," to which I respond, "why not?" and then a contentious debate about whether or not I can arrange the tapes on my own ensues. Dad claims he doesn't want me to do it because he is incapable at the moment. I try to explain to him what I'm doing and why. I continue arranging them while Dad sits in the same position until at 9:40 he drops his head, completely limp.

At 11:05, Dad mumbles something with the word "that" at the end, while looking directly at the cassette in my hand. I understand that he wants to know what the tape is, so I read out the title to him, "ne plus ultra" (**EI-1**). After taking a few moments, Dad starts an explanation of the English equivalent of this Latin phrase. Even though he is at the very lowest of his motor abilities during this time, he repeats himself many times over, louder each time until I understand the irony of naming a piece of music "Ne Plus Ultra," which means "None better than."

At 14:25, Dad begins slowly moving his arms and hands toward his coffee cup, a concerted effort that takes him until 15:28 to actually be able to form his grip and pick up the cup. At 18:45, Dad manages to say (with stutters), "pay pa paper please," while looking at a paper towel. I get up and give it to him to wipe his running nose (a perpetual side-effect of his medicine). Here, my understanding relies on **EI-1**.

At 20:28, Dad is looking directly at the carrying box for the cassettes and I am able to use the orientation of his gaze toward these objects (**EI-1**) in conjunction with **scaffolding** that allows him to fill in the words I'm missing. At 21:34, Dad corrects what I am doing and insists that the cassette labels face outward. At 22:38, he shows disapproval of the way I'm handling the

leftover cards and at 23:04, he takes up the argument about the cards facing outward again. At 24:02, I proclaim that I'm going to throw away the cassette boxes that are broken and although Dad is in the middle of a sip of coffee, he mumbles, but clearly opposes this idea (shown through tone of voice). I interrupt his objection and insist that I'm only throwing away the boxes that are completely broken and won't go back together. This is an ongoing fight we have had many times over the years anytime I try to help him sort through the cassettes. Here our shared **life narrative** is instrumental in making meaning. At 25:45, even though I've left the room, Dad is yelling to get my attention to tell me "thank you very much."

At 26:50, I start a new conversation about Charles going on the roof to check out the leaks. When Dad responds he is exaggerating his facial movements to an almost absurd extreme in order to speak. At 30:20, Dad calls me over to tell me I have marmalade on my shirt. He seems very concerned about this and he insists that I come closer so he can show me where (**EI-1**). As I near him, he tells me to turn slowly and then I realize he's talking about small colored flecks embedded in the threads of my sweater. It takes some time for me to convince Dad that the yellow flecks are not marmalade. This experience seems so similar to the "black bugs" Dad always seems to see on the cats (**life narrative**).

At 33:00, I bring Dad's bagel sandwich over to him and start feeding him. Dad's medication still does not seem to be working. At 37:38, Dad tries to feed himself but can't seem to get hold of the bagel. Charles sits by and watches Dad struggle. At 38:38, Dad actually manages to pick up the bagel himself. At 39:10, I sit down to eat my breakfast and ask Charles if he could help Dad with his meal since he's already done. At 39:46, Charles lifts the bagel for Dad. At 40:40, I again prompt Charles to help Dad with his struggle. At 41:48, Charles helps Dad again. At 43:56, I notice Dad's bagel has fallen apart. When I ask him what has happened to it, he makes a joke and says, "it's like the tapes." Charles goes to help him once he notices the bagel is falling apart. At 49:15, Mom gathers up Dad's bagel pieces and "wakes" Dad from his current state where his head is hanging down by calling his name. He sits up and she feeds him. During this interaction, I seem to interpret Dad's struggles with his bagels as meaningful on their own (**EI-2**). He doesn't need to ask for help verbally because I enlist Charles to do so.

Although Dad seems to be asleep (he is resting his head on his arm and is bowed down; he has been completely quiet for over five minutes), at 55:15, he initiates a conversation but what he says is unrecoverable except for the word, "tapes." I use scaffolding to get him to fill in the parts I'm missing. I eventually understand that he wants to go into the music room to see if there are any gaps in his shelves where missing tapes should be. It is interesting that he has been quiet while the rest of us carry on conversations about other topics, but he is still thinking about his tapes instead of participating in the new topic conversation. At this point, it seems Dad's medicine has kicked in and is making him dyskinetic (his head is now bobbing back and forth and his torso is rocking uncontrollably). Mom asks me to go get the email from Dad's sister to read it aloud for him. As I start, he abruptly stops me to get me to repeat a person's name he didn't understand. He participates in response to what I'm reading, adding more details. Philippa's email includes a forwarded letter from a cousin who travels the world. As I begin to read this embedded letter, Mom makes physical and verbal overtures to Dad to enlist his direct attention while I read. He is hanging his head over and his eyes are closed; he appears to be sleeping. Here Mom is using **EI-2**, to interpret meaning from Dad's actions, whether Dad

intended the meaning or not. Dad responds immediately and angrily and while most of what he says is not readily intelligible, after Mom says, “What?” I rephrase what I think he’s said saying, “he says he *was* listening until you started talking.” When Dad next has me repeat the main subject of the letter so far (the wedding in South Africa), he then asks, “Why weren’t we invited?” He seems to be making a joke in response to the letter writer’s comment that not so many American people came. Dad wonders how she could expect to have American visitors when they weren’t invited. At 59:00, Mom says “o.k., just listen,” opening the conversational space for me to just read without interruptions. After the bit of the letter concerning the wedding and honeymoon safari in South Africa, the author tells of their elaborate odysseys through Europe. At 1:00:00, Dad makes a commentary on the flowery, overdone and exaggerated letter, saying that it sounds like the time when the Grace Brothers folks went on vacation. He re-tells a joke from this Brit-com and starts laughing all on his own, as no one else can understand what he’s saying. My mother, Charles, and I all use **scaffolding** techniques as well as our ongoing **life narrative** (during the formation of which we have all watched many, many of the same Brit-coms together) in order to finally figure out that Dad’s joke is that “there are no hotels with no stars.” It takes us several turns and many repeats on Dad’s part before we can all laugh together.

3.13.07 B

This tape begins as I am already in the thick of reading a very long, flowery, exaggerated letter (nine pages, single-spaced) from one of Dad’s extended relatives (a cousin) who is spending her retirement traveling all over the world, redoing the insides of her house, and planning an exquisite destination wedding in South Africa for her daughter that includes a safari for all wedding attendees. I am dramatizing the letter somewhat as my family finds the letter nauseating for its bragging tone (particularly in contrast to how Dad is currently spending his own retirement). As Dad hangs his head over at the kitchen table after breakfast, I read and he interjects humorous comments. Our shared sense of humor that is drawn upon here is from our long history of our **life narrative** together. We also rely on the context of the letter to understand Dad’s comments. For example, at 00:22:00, he suggests that he should write them about his trip to Alaska in the same manner. After his commentary, he tells me to, “carry on.” Charles suggests that this reads like a travel brochure and Dad corrects him saying, “a travel *log*.” Dad bursts out laughing as I read aloud the menu description from a night in Greece. At 4:35, Dad finds especially amusing a bit of the letter when the author declares that she visited 92 churches in a week in Italy and then starts naming (what we think are) obscure pieces of art, sculptures, and churches as the highlights (as though we could have any idea what she’s referring to). I call Charles in to help me with the names of the Italian artists.

We continue to laugh our way together through every line of the letter as I read. Dad and I seem to find all the same things hilarious, based on our ongoing **life narrative**. At 8:32, Dad stops my reading to correct the poor grammar in the letter. Apparently the referent is not correctly juxtaposed next to the descriptor phrase in the sentence I’m reading. I then show Dad the pictures that came with the letter and Mom comes over to tell the story of who these relatives are. Dad contributes to this conversation by telling us that his cousin’s business is a kitchen remodeling company.

At 13:00, Dad says he now wants to go see his photos from their trip to Alaska and I improvise what our family’s letter about their trip would sound like if done in the same style. Mom

suggests that I should stop mocking and instead be friendly with this cousin because she would probably love to take us with her on her trips.

At 16:26, Dad suggests someone in Greece to stay with. Mom and I continue a conversation about places we'd like to travel. At 22:50, I ask Dad if he wants to stay in the kitchen or go into the living room. He mumbles, "living room," so I move him.

3.16.07

We are getting ready to eat dinner at the opening of this tape. Mom offers the use of their tripod for my video camera and Dad adds that he saw a cockroach run under it the night before last. This comment is understandable because we all have an ongoing **life narrative** about Dad's cockroach visions. I don't understand him at first, so Dad repeats. Dad then asks if he can see the film of himself when it's finished. Mom makes a comment about "needing Charles' brain while he's here," and while Charles responds sarcastically with, "so do I," Dad also makes a joke saying, "you'll have to locate it first." The black humor in this joke is part of our **life narrative** together as a family that Dad has been trying to initiate Charles into over the years. Mom wants Charles to set up the camera for them to look at their pictures from their vacation to Alaska.

Mom is feeding Dad his dinner for the most part. He feeds himself his asparagus. Dad is mostly quiet during this dinner except for one or two-word contributions. At 16:40, I move Dad out of the kitchen into the living room to watch Jericho.

At 18:04, the tape re-starts in the music room with Dad instructing me on how to arrange his CDs. He tries to make a motion with his hand to indicate how he wants them lined up (**EI-1**). As Dad is stacking his CDs, he starts a conversation with Charles about Ipods, calling it an E-pod at first. Charles demonstrates that he doesn't understand several times, so I come into the conversation repeating Dad's utterances for him (**scaffolding**). At 20:20, Dad asks me to move all the CDs to the kitchen table so he can sort through them. Charles wheels dad into the kitchen, but Dad stops him on the way to pick up a CD case that he wants me to put by the chair where he watches TV so he can glue it back together. I ask him if Mom's supposed to know about this or not (as I know from our **life narrative** that Dad often 'gets in trouble' for attempting complex tasks on his own). Charles leaves Dad alone at 22:00 when he hears the dogs causing trouble outside. Over the next few minutes, Dad tries to arrange his CDs and move his own wheelchair. I come back in at 24:20 and gather up his CDs to transport them into the kitchen for him. As Dad has made his way across the music room, I stop to reposition the camera. Dad is pointing to the different CDs to indicate which ones he wants me to transport (**EI-1**). He then tells me to get the box full of tapes by the printer to sort through. He also directs me to bring a particular binder with me, which I can understand because of my orientation to the physical space (**EI-3**). Dad continues to point to the tapes and CDs he wants me to find. At 28:30, I ask if his hand movement toward a drawer means that he wants me to open it (**EI-1**).

Around 30:00, we move Dad to the kitchen table to sort through all the CDs we've brought into the kitchen over the last half hour. At 31:04, Dad says something that sounds like "you oh atmu mubabaug me," and I say "yes, I know exactly what you're talking about," and then go to get the music bag I bought him. Even though Dad's phonological stream is not readily interpretable, it seems I understood him here because of our shared **life narrative**. I know that Dad always

uses a particular cloth bag with composers on it that I bought him during my last trip to England to put his CDs in that he carries with him every day to the Senior Center. I am able to recover the item of interest with ease because of our shared context.

At 33:50, Dad asks something and the only word Charles and I seem to understand is “lamp,” We use scaffolding to understand first which lamp he’s talking about and next what he wants us to do with the lamp. This scaffolding and negotiation takes us an entire minute.

At 35:00, Dad offers me a whole stack of CDs for free and I make a joke about how Dad will only give me CDs that came for free anyway inside his Gramophone magazine. Dad laughs along with me and then as I liken his gift to “giving me the toy out of a cereal box,” he corrects me by saying, “don’t be ungrateful.” We both continue to laugh.

At 35:26, Dad is trying to reach for a stack of CDs and winds up pushing a whole stack off of the table and onto the floor. I tell him, “Stop, Stop, Stop.” He then directs me to put an inner CD case inside an outer case while I’m already doing what he’s telling me to do. He continues directing me on which CD to put in what box, not allowing me to match up the CDs on my own (EI-3). Charles (36:40) comes into the kitchen to report on what he has found out about the lamp chore Dad asked him to do. Dad is saying the composers’ names and the names of the pieces, but I probably would not understand these without having the CDs in front of me (EI-1) and having a shared **life narrative** of these names being household names.

Dad continues pointing to direct my actions. During this process, Dad’s speech is quite close to mumbles, but the physical context helps me to understand what he wants me to do (EI-1). I also point to particular CDs and cases in order to contextualize my own talk. Dad’s head nodding and gaze also are instrumental in creating a mutual understanding.

At 46:20, we use scaffolding. Dad says something about a CD and a car. As we negotiate meaning, I keep repeating the only parts that I understand of what he says. Dad even imitates the sound the CD player in the car made to aid my understanding of the situation. It takes us until 47:25 to achieve understanding.

At 48:50, Dad makes a hand movement of sweeping to tell me what to do to the CD in my hand (EI-1).

At 51:00, Dad asks Mom about the CD that was in her car stereo, but she doesn’t seem to know what he’s talking about. I fill in more details about the CD because Dad and I have just managed to establish this information in the preceding conversation. Charles also comes over to help find the missing CD in the car and I am able to give him extra details about what to look for in the car because Dad has already explained them to me. Dad doesn’t offer any details himself. Here it seems like Dad and I have built an ongoing narrative and we just continue to build on it so Dad doesn’t have to start over from the beginning with Mom and Charles.

At 52:15, Mom comes back from looking for the missing CD in the music room. She is explaining to us what she thinks she did with it, as though she is accountable to Dad for losing his CD.

At 58:20, Dad starts a conversation about one of the CDs that is still missing its case. I seem to rely on the physical object and Dad's orientation to it to aid in my understanding. I finish up the arranging of the CDs and carry them back into the music room while Dad sits at the table. At 1:01, he tries to reach for the book and CD case I have left at the opposite side of the table, but in his attempts, he ends up pushing them further away. He tries to reach them several times but cannot. When I come back in the room, I pick up these objects and remove them without Dad saying anything.

4.08.07 A

Dad is mostly in a black hole, but he is trying to fix the wheel on his wheelchair. The wheelchair is turned upside down and Dad is kneeling over the wheels. All his utterances are extremely belabored because he is expending all his energy on trying to slip the tire back onto the wheel. I can only understand anything he says because he is either pointing to, looking at or talking about the tires or wheels. The only two readily intelligible words are "dry" and "wet", which in combination with the context of the wheelchair and our physical orientation to it, become understandable. I can figure out their meaning only based on **EI-1**. I seem to realize that he wants to add some sort of wetness or lubrication to the wheels in order to slip the tire on.

At 7:40, the only intelligible word is "up", which said in context of the physical environment (Dad is facing an armchair with his hands on the arm, trying to lift himself). I understand that he needs me to help him up into the chair. Here I rely on **EI-1** to help my understanding.

Once Dad is in the armchair and I am fiddling with the wheelchair, Fizzdale the cat comes over to me. I pick him up and Dad starts telling me to move him around so I can look at his leg and his foot, which (according to him) have fleas all over them (**EI-3**). This conversation has nothing to do with our previous utterances of the day, but Dad has initiated conversations just like this before, where he is sure there are thousands of fleas running around on the cats. Mom mentions having these same conversations with him and believes that either the Parkinson's disease or his medications make him have vision problems or minor hallucinations (**life narrative**). During this interaction, Dad's words are mostly unintelligible and I am able to understand what he means because of our shared history on this same topic and because I am holding the cat in my arms while he directs my attention to it with his gaze and pointing (**EI-1**).

At 16:30, Dad spills coffee in the music room and I rush to clean it up before Mom finds out.

At 17:15, Dad is back on the floor and kneeling, with his hands on the arms of the wheelchair. He says something unintelligible and then tries to say a word with "stea -stan" at the beginning. Based on the physical context, I understand that he wants my help getting up into the chair (**EI-1**). Once he is in the wheelchair, he begins a statement with the "sh" sound while pointing and looking at his shoes that are in the pathway of the wheelchair. I understand that I need to move the shoes and ask if he wants me to put them on him. This interaction relies heavily on **EI-1** as Dad directs my attention to objects in our physical surrounds.

We go out to the kitchen for tea and have a short conversation about watching TV the night before. He makes a comment I don't understand, so I use **scaffolding** to aid our conversational exchange.

At 29:58, I ask how the wheel came off. He makes a joke about the wheel which I understand because I already know about the wheel popping off from hearing Mom's version of the story earlier in the day (**life narrative**).

At 31:00, I ask about letting the cats outside onto the screened-in patio, to which Dad responds along the lines of "afta as mutter". This is a common phrase Dad has employed during my entire lifetime whenever I ask a question he knows he could get into trouble for answering. Although the sounds of his utterance are not readily intelligible, I can understand it because the sounds make sense in the context of the ongoing speech and based on the context of my lifetime during which Dad has always deferred responsibility on major decisions to my mother (our family's **life narrative**).

At 39:00, Dad makes a joke about Fizzdale saying, "He thinks the dogs will pet him." I don't understand for 4 turns where I say, "what pet him" and then dad repeats twice and then I **scaffold** again with, "He thinks the dogs will..." This joke relies on our **life narrative** and **EI-1** for our understanding.

At 41:26, Dad starts in about "two things on [Fizzdale's] back, which is not directly relevant to the ongoing talk, but actually relates to the conversation about the cat's fleas from the beginning of the tape. We discuss whether or not the fleas are in his imagination or a problem with his vision. I comb the cat and show Dad there are no fleas on the comb. I consider this to be a case where both **EI-1** and our **life narrative** factor into our understanding.

At 46:00, Dad shoots his hands straight up in the air while directing me to the top shelf of the bookshelf. Dad is still seated at the kitchen table and I am walking through the kitchen on my way to the music room. He is using his body to direct me to a spatial orientation once I get in another room (**EI-4**). He talks about "Il Maestro di Capella" and about trying to get the Greenville Symphony Orchestra to play it. I understand now why he wants me to find the libretto.

At 50:18, we have a miscommunication when Dad asks a question about the temperature and I falsely assume he is making a statement about something we've been talking about. I then hear the word 'train' and figure out that Dad is saying, "like a train that turns around". I don't know if I ever truly understood what he meant here.

At 53:40, Dad says something like: [xxx]..English at all while looking at a record sleeve. I ask, "He's not English at all?" To which Dad replies, "not *in* English. I say "no?" and then get the record sleeve and make a commentary about the other different languages that are on the sleeve: German, Italian, French. Here, we rely on both the physical context of the record album (**EI-1**) for understanding.

4.08.07 B

At 1:28, Mom raises her glass at the dinner table and says, “Happy Easter. Thank you for coming. As Charles, Mom and I all lift our glass doing the “cheers” motion, Dad attempts to say something and points toward his own wine glass (**EI-1**). It sounds like he says either “help me” or “give me some” so Mom raises his glass for him and brings the glass in her left hand forward to clink out “cheers” with the rest of the glasses. Here Dad’s comments and gestures have directed Mom to allow him to vicariously participate in an activity through her (**EI-3**). I make a comment about how Dad’s hand needs to be on the glass, but Dad moans and looks intently at his glass. Mom paraphrases what she thinks is Dad’s intended meaning from his moan and glance when she says, “he’s more concerned about drinking it” (**EI-2**). She laughs while she takes his wine glass to his lips. This interaction relies heavily on anchoring Dad’s gestures and gaze to particular objects and events in his surrounds (**EI-I**).

At 2:01, Dad says something to Charles that he doesn’t appear to understand. Before Charles has a chance to ask for clarification, I say, “what?” Mom seems to know what Dad wants to say, so she starts telling about drinking this particular wine when we used to live on Long Island. Mom says the wine was less expensive then and at 2:17, Dad chimes in the old price. Mom and Dad co-tell this story and comment on the wine together. They are able to supplement each other’s speech based on the **life narrative** they have established during their lives together.

At 4:20, Dad reorients to the wine bottle and makes a comment about the wine. I am looking at the label of the wine bottle when I ask, “Where’s Harrison, NY?” Dad’s answer about the city’s location seems interpretable only because I know the area around New York where we used to live (**life narrative**) and because we have established a context that leaves a slot for the description of a location. His phonological stream sounds almost completely uninterpretable.

At 5:22, I tell Charles a joke I made up that is a play on words in Italian. When mom says that’s Spanish, not Italian, Dad corrects her and then explains why.

Mom is feeding Dad during this meal. He has to wait for her attention to be fed a next bite. At 6:17, Mom picks up his spoon and asks him if he can hold it himself. Dad bites his lip at 6:30 and we all laugh afterwards about how the look on his face when he did it looked like he was blaming mom for his having done it.

At 8:20, Dad asks if I cooked the rice in vinegar. He has to repeat himself in order for me to understand. Charles tells the family about his day at a seminar on Chinese Medicine. After Mom asks if Charles was allowed to record it, Dad adds that “you could probably get sued for half the stuff that’s on there,” (12:12). We seem to all ignore him and talk about something else, so at 12:25, Dad repeats himself with incredible clarity, which does elicit a response from me. Dad continues to participate in the conversation about the sounds recorders make while recording. He seems to be in good spirits and to be feeling relatively well. This in turn seems to be affecting his participation in the conversations. Charles is talking about patients that came into the Chinese medicine seminar and then I turn the conversation to a discussion of Dad going in to be treated.

At 14:20, it is clear that Dad is starting to choke or just needs to cough while he’s eating. As he starts coughing and trying to hold his mouth closed, Mom says, “you’ve got a hand,” which seems to make him lift his hand up to his mouth and turn his head from the table.

At 14:38, Dad (quite appropriately for the ongoing conversation) asks me, “Did you hear about that nun who got cured of Parkinson’s Disease because she prayed to the pope?” He then has a surprise recurrence of his coughing fit and he can’t seem to get his hand to his mouth quick enough. Mom reproaches him for this saying his name somewhat disdainfully. Dad then continues to tell the story about the nun, but he keeps getting interrupted by his coughing spasms. Mom fills in the story while Dad takes breaks to cough. The apparently saw this news segment together (**life narrative**). Mom then explains that this is a second miracle for the old pope and that he only needs one more miracle before he can be a saint so she figures Dad could be the next one. She jokingly says she’s decided to convert to Catholicism. Dad then starts a new, but related story at 15:30, but mom keeps telling the story of the nun. Charles responds directly to what Mom is saying, so Dad looks directly at me for attention. I nod my head and raise my hand to point to him to indicate that I am listening despite the cross-talk. Dad then gains the floor to tell his story. The only words I can understand when listening to the tape are “baby” and “pregnant.” As mom puts a huge mouthful of food in Dad’s mouth, She says, “Did you remember=,” which I abruptly interrupt saying, “wait a minute, I’ve got to hear what Dad’s saying.” Using a form of scaffolding while Dad chews and swallows, mom says, “who was pregnant?” and I then offer my understanding so far: “someone had a baby and shortly thereafter the baby become pregnant is what I understood from what you said (laughing).” With no other substantial contributions from Dad, Mom is immediately able (at 15:55) to recognize the makings of a joke she has heard many times in their life together (life narrative). After Mom says, “Are you trying to tell that joke?” Dad says, “Yeah,” and I ask him to tell me again. Dad says something that is somewhat intelligible about a couple going XXXX and then seven years later XXX again. Interestingly, this is enough information for me to be able to identify the joke myself. I say, “Oh I know this one,” and then tell the gist of it to Charles after clearing my recollection of it with Dad. Dad corrects me once at 16:30. Mom then reorients to the nun story and says that this story is true.

The conversation segues into a discussion of praying for each other in church and privacy laws that prevent the mentioning of peoples’ names. As Mom continues to feed Dad, he stops her from giving him any fish skin by telling her to take it off his plate. She insists there is no skin on the fish and then he looks intently at his plate until at 19:22, as mom is turning over the food with the spoon, he points directly at a particular spot and says, “there’s a bit, there’s a bit” (**EI-1**). I make a joke at this point which may be considered inappropriate: “It’s right there, next to the cockroach and the flea.” In my joke I am intending to reference Dad’s uncanny ability to constantly see things that no one else sees. I am referring in particular to Dad’s weeks of hallucinations where he saw cockroaches everywhere and to the thousands of fleas Dad always says he sees on the cats. This joke and my family’s understanding of it is based on our **life narrative**. As I got no reaction from my joke, I go on to explain that I spend “half my time here trying to prove to Dad that there’s not 800 fleas on the cats. Mom says she spends every evening doing the same thing. I go on to explain that it’s when he sees their fur pushed back and it gets a black look to it. At 19:55, Dad insists that the black objects are moving and I then insist that it’s their fur moving. I am taking so much effort to explain this and Dad starts laughing at me. Charles and I also start laughing and I stop my explanation. Mom says, “the other night he told me they were on my hand.” At 20:32, Dad asks “Could I have more wine, Charles,” but Charles seems not to know he’s being addressed. The three of us are occupied trying to get the cat to eat some salmon. Dad repeats his request for wine but we don’t ever hear him. Dad waits for a lull in

the conversation and then at 21:34, Dad looks at Charles and tries his request again. At 22:06, Dad asks mom to feed him another bite. At 22:46, Mom makes a joke about Dad setting my alarm clock for me. This is based on another ongoing family conversation (**life narrative**) about how each time Dad tries to manipulate his CD player and clock radio on his own, he accidentally messes up the time and the alarm goes off at random times in the middle of the night, waking my mother in a panic. I continue the joke saying that, “yeah, he could do that if I want it to go off at 2 in the morning.” Mom and I are the only ones who laugh. At 24:12, Dad points to his wine glass and mom lifts the glass to give him a sip (**EI-2**). At 24:35, Dad tells us that they’re going to see Gil Shaham the next evening and then he gets emotionally choked up while telling us he’s the best violinist in the world. Mom says she’s never heard of him and Dad replies saying, “He’s Israeli.”

At 26:18, Dad makes a joke about trading our oldest dog who doesn’t really move at all for his cat. At 27:25, he says the cats sleep all day and all night – at least 18 hours a day. At 28:12, Mom makes a joke about having to drop Dad off at the nursery the next day. She starts a conversation about one of the men at the day care center who is always ‘working’. She discusses how anyone on Medicaid can be paid to go to the center. Dad asks for wine again at 31:44. At 33:20, Dad imitates Fizzdale’s growl as a joke. All the joking that takes place in this part of the conversation relies on our shared **life narrative** about our dry sense of humor.

At 37:20, Dad makes a comment about watching TV with mom. He tries to say that “she skips away from programs that look as if they’ve got any progress.” In order to understand what he’s saying, I use **scaffolding** several times to get him to repeat specific parts of his utterance. Dad feeds himself his strawberries and ice cream while the rest of us work in the kitchen and clear the table. At 45:38, Dad asks if his urinals are beside his bed, which turns into an open discussion about Dad’s bowel and urinary necessities in front of Charles and me. Mom takes Dad away from the table and into the bedroom to the bathroom.

The next morning, I tape while we are having breakfast. I read aloud a part of the paper Dad is looking at. Dad has asked me to play some classical music CD for him and the player is right next to where I’ve placed the camera, so our talk is mostly inaudible. The one time I try to turn the volume on the music, Dad gives me a disdainful look letting me know he disapproves (**EI-1** and **life narrative**). I turn the tape off once I realize the futility of taping alongside such din.

6.09.07- 6.10.07

This video records two outside meals. The first takes place on the ninth at dinner and the second takes place on the tenth at brunch. At the beginning of dinner, Dad looks desperately stuck. His medicine does not seem to be working at all. At 1:08, I finally sit down and ask him if he’s ok, and he simply nods his head in response (**EI-2**). Dad seems to be leaning forward in his chair against his will. I am making his hamburger and he mumbles quick one-word responses to my questions about how he’d like his burger made. At 1:57, I pass his burger to him, yet he can’t grasp it at all. I’m busy assembling my own burger so and at 2:48 when mom comes out, she sees he needs help and goes to feed him (**EI-2**). At 3:58, I realize that Dad needs another bite and I ask Charles to feed him. At 4:57, Charles asks Dad again if he’s ready for another bite and then feeds him (**EI-2**). At 6:36, I stand up and give Dad another bite of his hamburger as Charles has gone inside. Dad seems to be struggling just to sit upright and chew, so he is not offering any

contributions to the conversation. He sits and waits for others to notice that he needs to be fed instead of asking for help. At 9:00, I stand up and go around to feed him a bite again. At 9:42, Mom grabs his right arm and tries to pull him up in his chair. This has the effect of making him lean forward in a different direction rather than rectifying his problem sitting upright. Mom takes over responsibility for feeding Dad at 11:05. At 14:32, Dad announces that he has to go to the bathroom, even though we are all still eating. At first, he says that he can wait, but then I offer to go ahead and take him as I'm already finished eating. I get up and take him back inside.

A problem with this tape is the outdoor filming. There are too many background noises that the microphone is picking up, including the sound of the cicadas. Everyone is completely audible on the tape except for Dad, as he is having trouble phonating because his medicine isn't working. As I leave Dad inside to do his business, I go back outside and talk with Mom and Charles. Mom is explaining how Dad crawled up the stairs the day before to check out the work she had done redoing our bedroom. I mention that Dad was in a bad mood from the very first moment this morning because we all made plans for the day without including him in the discussion. Mom explains that Dad's father was always the same about being left out of family plans. At 20:01 I get up to check on Dad and find that he is still busy. As I go inside again, Mom explains to Charles how it "breaks her heart to watch him throughout the night." She says that in the morning, he insists he can dress himself, so if she lays his clothes out for him and then comes back thirty minutes later, he is still looking for the label in his pants. She goes on to explain her routine of dressing him in the morning. She says she does everything for him except putting on his pants so that he can still feel like he's dressing himself. Mom explains that he is involved in physical and speech therapy now and that they are both wearing him out. At 22:35, Charles summarizes his previous conversation with Dad saying that Dad feels like he exercised muscles he hadn't used in years when crawling up the stairs the day before. Mom explains that going up the stairs was so difficult for Dad because the time of day when he went upstairs was a time when his medicine was "out."

I bring Dad back outside at 23:43 and at 24:00, Mom tells him to "sit up please." Attempting to defend him, I say, "he can't," and Mom retorts quickly, "yes he can," while pulling his arm to sit him upright again. She tries to give him instructions on how to sit up. Mom, Charles, and I continue a conversation about our plans for the next day while Dad just sits there. At 32:15, Dad tries to say something to Mom, but she doesn't understand. Several times, she says, "what?" then "you're not putting any air out," and then all three of us have to use **scaffolding** in order to understand Dad's full meaning. Mom argues Dad's point about how he feels like he does tonight because of last night's trip up the stairs. Mom asks if he's done his exercises today. During the entire interchange, it is extremely difficult to understand what Dad is saying. At 34:30, I move the camera closer and sit it on the table. At 35:20, Dad makes a comment about the camera placement. We all go inside shortly thereafter, so I turn off the camera.

The next morning, we are eating outside again and Dad seems to be much more active. He is able to feed himself, including managing toast in one hand and eggs on his spoon in the other. At 39:20, I address Dad and tell him about a sociology study of people who left their cell phones in pubs and Dad doesn't seem to pay me any attention at all, but rather goes about his eating.

At 44:35, Mom tries to wake Dad up (he looks like he's fallen asleep in his chair – **EI-2**) by saying, "Peter, have you had any of your bacon?" He picks up his bacon and takes one bite and then appears to go back to sleep again with his bacon in his left hand. At 47:15, Mom makes eye contact with me and then points to Dad as though wanting to point out how he falls asleep in the middle of eating, Dad may or may not see this hand motion she makes.

At 51:00, Dad helps add facts to the story Mom is telling about long-time friends of theirs. For about five minutes, Dad is vigorously petting Tess with his right hand while eating his bacon with his left. Mom and Charles and I have a debate about homosexuality while Dad eats and drinks his coffee on his own.

I turn the conversation to talking about ipods for Dad. Dad begins to participate in the conversation here (56:00), saying that he wants on that he can even watch the news on.

We go on to a conversation about our plans for the day and at 59:50, Dad states that he wants to go to the Bose store at Cherrydale. Mom and I use **scaffolding** to fully understand him. Charles starts sharing his dream from the previous night with us and then the tape ends.

6.10.07

As we begin our dinner outside, Mom asks if I can arrange the camera for her to be out of view (she has her hair in curlers and is already in her nightgown). Mom is feeding Dad his meal as he is leaning forward and resting his arms on the table. It is difficult to hear Dad's comments on this tape because of his problems with phonation and the fact that the camera is furthest from him. My camera placement would have benefited from my watching the videos from the previous day before taping again. If I would have watched the previous day's footage, I would have been aware of the sound issues and could have remedied it by placing the camera differently.

At 6:04, Dad participates in our conversation about Jupiter, asking questions that Charles need him to repeat for him to understand. At 8:15, Dad says, "Beer please," and as Mom reaches to lift the beer to his mouth, she asks, "you can't do it?" Dad starts a conversation about a beer that was made in Mom's hometown.

Charles, Mom, and I have a conversation about the cottage we'll be staying in around Traveler's Rest while Dad listens. After a lull in the conversation, at 20:00, Mom says, "Peter, can you sit up, please?" Dad appears to be trying to sit up when Mom then says, "can you sit back?" and then quickly follows it with, "Do you hurt today?" It sounds like Dad responds with "yes," and then he mumbles something further that sounds unintelligible. I then say, "You sound like Boomhauer," (the mumbling character on the comedy cartoon, King of the Hill). Mom agrees and says that she's told him that, too. I add that he sounds like a British Boomhauer and Dad doesn't appear to react at all. This is based on our shared **life narrative**, as Dad has suggested before that he sound like Boomhauer.

Mom turns the conversation to a discussion of Dad's sleeping habits and says that he pulled the sheets off the bed again last night. Dad makes no comment or reaction.

At 22:01, Mom turns to Dad and (based on his inability to move with any ease) says, “Do you think the Stalevo (a Parkinson’s medication) is not working anymore?” (EI-2). Dad is trying to manipulate the foot pedals of his wheelchair at this point. He replies, “I don’t know.” He doesn’t seem able to sit back up after leaning down to fiddle with the foot pedal.

At 24:54, Mom rephrases Dad’s comment about his corn for Charles and me to understand. Dad tries to grab for his corn on the cob for himself and Mom stops him from eating it, telling him he’ll have to wait until it cools down. Around 27:30, Charles, Mom and I have a discussion about the best way for Dad to eat his corn. Dad doesn’t participate in this discussion that is about his own food and eating.

Around 29:40, Dad appears to be having increased difficulty sitting upright. He has almost completely fallen over to the right and at 29:56, I ask, “Do you need to sit up straight?” Dad answers, “yes,” and I quickly offer, “Do you need Charles to re-situate you?” (EI-2). Charles gets up to help as Dad says something that I only partially understand. Using **scaffolding**, I repeat this bit that I do understand with a question intonation at the end. Dad moans and demonstrates discomfort as Charles moves him. Mom and I debate what’s going on: I insist Dad can’t help what he’s doing and Mom says that after you lean like this for so many years, this is what makes your spine break. Mom tells Dad how to sit and where to put his arms while Charles massages his shoulders. Dad is then poised to eat his corn-on-the-cob on his own.

At 34:56, Charles points out to Dad, “you’re eating the core there, Peter,” indicating to him (his vision is often blurred) that he is already done with his corn. Mom takes the cob from him and says, “Peter, you’re eating the cob.” (EI-2). Mom then cuts the remains of the corn off the cob. As Mom cuts it off, I ask, “Do you prefer to eat it off the cob, Dad?” He responds saying something that is mostly unintelligible, but a vague, “yes,” does seem to emerge from his stream of speech. Mom tries to rephrase what he’s saying and tells me he’s talking about the dog barking, but Dad immediately corrects Mom and says “I was not – I was talking about the corn.” Mom says she was just trying to help him.

At 51:00, Dad manages to reach for his beer mug and drink his beer on his own. Around 51:50, Mom realizes this and says, “Good Job. Has the medicine kicked in?” (EI-2). Dad says, “no,” and I offer that, “he just needed his beer.” At 52:00, Dad asks Charles twice to add some beer to his mug by moving the mug into Charles’ view and nodding toward the mug and the bottle.

I get up from the table and start moving Mom’s houseplants outside for the summer. At 54:00, Dad starts directing me. He is pointing and looking at specific plants and objects on the patio, which aid in my understanding (EI-1).

At 59:20, Dad starts a new conversation topic with Charles, talking about his school program. Charles has a very difficult time understanding him and uses **scaffolding** and clarification requests to achieve understanding.

APPENDIX D: CONSENT FORM

I, _____ agree to take part in a research study entitled, “Finding common Ground: *An Analysis of Communication Strategies of a Parkinsonian Aphasic*”, which is being conducted by Amy Heaton of the Linguistics Department, Franklin College of Arts and Sciences, (706) 207-6540, under the direction of Dr. Betsy Rymes, of the Language Education Department in the College of Education , (706) 542-4525. My participation is voluntary. I can stop taking part at any time without giving any reason, and without penalty. I can ask to have information related to me returned to me, removed from the research records, or destroyed.

Item #1: Purpose

The purpose of this study is to shed light on communication problems and strategies that arise when speaking to a subject with Parkinsonian Aphasia.

Item #2: Benefits

The only benefit the participant will receive in compensation for his or her participation is spending more time with family members. There are no other expected benefits to the participants.

Item #3: Procedures

The research will consist of videotaping and audio-taping the subject while he interacts with his daughter and goes about some of his normal daily activities. The subject may be asked to work on specific projects with the research conductor such as filing household paperwork or working on photo albums. The videotaping sessions will be no longer than two hours in length and will take place from March 2005 until August 2006 at the subject's convenience.

Item #4: Discomforts or Stresses

No discomforts or stresses are expected. If at any time the subject is tired, he may say so and the research will be terminated and rescheduled.

Item #5: Risks

No risks are expected.

Item #6: Confidential, Anonymous, or Public

The identity and results of the participant's involvement will be made public.

Item # 7: Further Questions:

The researcher will answer any further questions about the research, now or during the course of the project, and can be reached by telephone at: (706) 207-6540.

Item #8: Final Agreement and Consent Form Copy:

My signature below indicates that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have been given a copy of this form.

Item # 9: Signature

Name_____ Date_____

Please sign both copies, keep one and return one to the researcher.

Item # 10: IRB OVERSIGHT PARAGRAPH

Additional questions or problems regarding your rights as a research participant should be addressed to the IRB chairperson in the Human Subjects Office at the University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411. Telephone: (706) 542-3199; E-Mail Address: IRB@uga.edu

