

FAMILY VOICES: ANALYSES OF TALK IN FAMILIES WITH
ALZHEIMER'S DISEASE OR A RELATED DISORDER

by

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ABSTRACT

It is widely recognized that communication difficulties pose significant problems for family members of people with disorders of progressive cognitive decline, such as Alzheimer's disease (AD). To date, however, relatively few studies have explored these problems in the context of everyday conversation in family life. The goal of this qualitative study was to explore changes in family conversation associated with a diagnosis of progressive cognitive decline, the meanings associated with those changes for family members, and the implications of those meanings for the family as a unit. The project comprises case studies of two families, one including a woman with AD, her husband, and their three adult children, the other including a woman with nonfluent progressive aphasia, her husband, and their four adult children. Methodology was based on symbolic interactionism and conversation analysis, exploring meanings both as conscious reflection and also as constructions of everyday talk. Constant comparative analysis of interviews conducted with each family member identified meanings that he or she gave to the diagnosis and changes associated with it, highlighting how consistencies and contradictions in those meanings were interwoven within each family unit. Analysis of audiorecorded conversations between the diagnosed person and other family members highlighted how those meanings were constructed in their talk together. For the family with AD, a key finding, discussed in terms of positioning theory, was how the family negotiated changing roles through everyday talk; for the family with progressive aphasia, a key finding, discussed in terms of theoretical considerations of silence, was how family interpreted and accommodated to their affected kin's diminishing talk. Communication accommodation theory provided a framework for discussing the findings for both

families, exploring the ways in which members sought to maintain conversational coherence while respecting relational demands for politeness. Finally, because each family was considered as a unit, the findings offer new insights into the nature of family care and support in the context of disease. Together, these case studies inform our understanding of dilemmas, challenges, and strategies for families coming to terms with progressive cognitive decline; the relevance of these findings for clinical practitioners is also addressed.

TABLE OF CONTENTS

ABSTRACT	II
TABLE OF CONTENTS	IV
LIST OF TABLES	IX
LIST OF FIGURES	X
LIST OF EXCERPTS	XI
ACKNOWLEDGEMENTS	XIII
CHAPTER ONE: INTRODUCTION	1
Overview of the Study	4
CHAPTER TWO: REVIEW OF THE LITERATURE	6
Constructions of Disease and Diagnoses.....	6
The Emergence of Alzheimer's Disease as Diagnostic Category	7
The Emergence of Alzheimer's Disease in Public Discourse	9
Biomedical Descriptions of AD and Related Disorders	11
The Evolution of Alzheimer's Disease as a Diagnostic Category	12
The development of standardized criteria	12
Staging and symptomatology of Alzheimer's disease	13
Further shifts in the evolution of AD as a diagnostic category	16
Progressive Aphasia.....	18
Clinical characteristics	20
Symptomatology of nonfluent progressive aphasia	21
Disease progression and outcomes	22
Alternative Constructions of Alzheimer's Disease and Progressive Aphasia	23
Diagnosis of Disease and the Experience of Illness	23
Alzheimer's Disease and Social Interaction.....	27
Alzheimer's Disease and the Family	31
The Concept of Family Caregiving	32
Who/What is Family?	32
Who/What is a Caregiver?.....	33
The Study of Family Caregiving in AD	35
Individual Family Members as Caregivers	35
Caregiving in the Family	40
Emergence of the Person with AD as Family Member	43
Families, Alzheimer's Disease, and Conversation	44
Accommodating to Linguistic-Communicative Breakdowns	44
Roles, Relationships, and Alzheimer's Disease in Family Conversations	47

Framing the Research Question.....	48
CHAPTER THREE: METHODOLOGY.....	51
An Interpretivist Orientation.....	51
Symbolic Interactionism	52
Conversation Analysis: Talk-in-interaction as Social Order.....	54
Interactional Sociolinguistics: A Focus on Meaning	56
Diagnosis, Family Life, and Conversation in Family Discourse: Two Approaches	57
The Case Study.....	58
Procedures	60
Participants	60
Ethical Considerations	61
Data Collection.....	63
Interviews	63
Conversation Recording.....	64
Participant Observation.....	64
Journals and Diaries	65
Data Analysis	65
Transcription	66
Key Concepts as Objects of Talk: Analysis of Interviews	67
Key Concepts as Process of Talk: Analysis of Conversations	69
CHAPTER FOUR: EMERGENT FINDINGS.....	73
Introduction	73
Study Participants.....	73
Recruitment Process as a Reflection of Family Style.....	76
Conversational Data.....	77
Tanaka Family Conversations	78
Thompson Family Conversations	79
A Clinician's Perspective.....	81
Clinical Descriptions.....	82
Rose Tanaka and Alzheimer's Disease	82
Margaret Thompson and Nonfluent Progressive Aphasia.....	83
Challenges in Interviewing Participants with AD and PPA	84
Rose: Challenges in Maintaining a Common Frame	84
Margaret: Challenges in Elaborating Meaning	87
CHAPTER FIVE: THE TANAKA FAMILY AND ALZHEIMER'S	90
Alzheimer's Disease: Diagnosis and Expectations	90
Interview Representations.....	90
Representation of Alzheimer's	92
Diagnosis as Explanation.....	95

Diagnosis as Strategy	97
Diagnosis and Expectations	99
Conversational Constructions	100
Conversational Behaviours as Symptoms and Strategic Accommodations	100
Conversational Constructions of Alzheimer's	108
Alzheimer's in the Family	110
Interview Representations	110
Solidarity and Mutual Support	110
Changing Family Roles and Attributed Reactions	115
Coping Strategies and Ethical Challenges	118
Conversational Representations	122
Changing Places	123
The Family Cook	127
Taking Care Of or Taking Over?	133
Alzheimer's and Conversation	140
Interview Representations	140
Tom: "There's No Point"	141
Colin: "Filling Up The Conversation Time"	142
Linda: "We Don't Have Conversations Anymore"	143
Maria: "You Find Ways"	145
Rose: "I Don't Even Think Of It"	146
Integrating Accounts of Conversation	146
Conversational Representations	148
Two-sided Small Talk: Multi-party Conversation with a Stranger	149
A Shared World: Multi-party Family Conversations	156
Two-Party Conversations: Differences in Obligatory Talk	166
Two-Party Talk: A Challenge to the Management of One-sidedness	174
Summary	178
Commentary	180

CHAPTER SIX: THE THOMPSON FAMILY AND PRIMARY PROGRESSIVE APHASIA..... 185

Primary Progressive Aphasia: Diagnosis and Uncertainty	185
Interview Representations of PPA as Diagnosis	185
The Process of Diagnosis	185
Diagnosis as Explanation: Representations and Mismatched Perceptions	188
Diagnosis and Uncertainty: Alzheimer's Disease and Unknown Expectations	193
Conversational Constructions of PPA as Diagnostic Category	198
Speech Patterns as Symptoms and Accommodations	199
Talking about Primary Progressive Aphasia	203
Primary Progressive Aphasia in the Family	205
Interview Representations	205
A Family of Individuals	205
PPA: A Threat to Accomplishment, A Threat to Individuality	206
Respecting Individuality while Speaking for Another	209
A Family Response to Primary Progressive Aphasia	211
Conversational Constructions	213
Supporting Accomplishment	214

The Complexities of Speaking for Another	217
Reconnecting.....	226
Primary Progressive Aphasia and Conversation.....	230
Interview Representations.....	230
Characterizing Conversations	230
Accommodations to Difficulty and the Meaning of Conversation	231
John and Margaret: Frustrating communication and lost conversations.....	232
David and Christine: A preference for joint interaction.	234
Stephen and Angela: Keeping conversations going.	236
Conversational Constructions.....	239
Conversation as Performance: The Importance of Language	239
Making Space.....	243
Marking Presence.....	249
Summary.....	254
Commentary	255
CHAPTER SEVEN: DISCUSSION.....	260
Conversational Accommodations in the Context of Disorder.....	263
Family Networks and Caring.....	273
Support, Care, and Caregiving.....	274
Individuality versus Family Belonging	276
Implications for Clinical Practice.....	280
Limitations of the Research Study.....	284
Directions for Future Research.....	284
Conclusion.....	285
REFERENCES	288
APPENDIX A: CONSENT FORMS AND CERTIFICATE OF APPROVAL FOR ETHICS	305
Consent Form for Person with AD or PA	305
Consent Form for Family Members	308
Certificate of Approval for Ethics	311
APPENDIX B.....	312
APPENDIX B: INTERVIEW GUIDE	312
APPENDIX C: SCHEDULE OF DATA COLLECTION	313
Interview Data.....	313
Participant Observations	314
Conversational Recordings	315

APPENDIX D: KEY TO TRANSCRIPTION	316
APPENDIX E: TANAKA FAMILY TRANSCRIPTS	318
Transcript 1: Christmas.....	318
Transcript 2: Thailand.....	320
Transcript 3: Swans and Ducks	323
Transcript 4: Photo Show.....	325
Transcript 5: The Kootenays.....	330
Transcript 6: The Past	335
Transcript 7: The Casino.....	340
APPENDIX F: THOMPSON FAMILY TRANSCRIPTS.....	342
Transcript 1: Aphasia and the Piano.....	342
Transcript 2: Four pianos, two hands, and two storytellers.....	344
Transcript 3: Fruit Leathers	346

LIST OF TABLES

Table 4.1.....	78
Table 4.2.....	80

LIST OF FIGURES

Figure 4.1.....	74
Figure 4.2.....	75

LIST OF EXCERPTS

Excerpt 4.1.....	85
Excerpt 4.2.....	88
Excerpt 4.3.....	89
Excerpt 5.1.....	101
Excerpt 5.2.....	102
Excerpt 5.3.....	103
Excerpt 5.4.....	103
Excerpt 5.5.....	104
Excerpt 5.6.....	105
Excerpt 5.7.....	105
Excerpt 5.8.....	106
Excerpt 5.9.....	107
Excerpt 5.10.....	108
Excerpt 5.11.....	109
Excerpt 5.12.....	123
Excerpt 5.13.....	124
Excerpt 5.14.....	125
Excerpt 5.15.....	126
Excerpt 5.16.....	127
Excerpt 5.17.....	129
Excerpt 5.18.....	131
Excerpt 5.19.....	132
Excerpt 5.20.....	134
Excerpt 5.21.....	135
Excerpt 5.22.....	137
Excerpt 5.23.....	138
Excerpt 5.24.....	150
Excerpt 5.25.....	152
Excerpt 5.26.....	154
Excerpt 5.27.....	157
Excerpt 5.28.....	161
Excerpt 5.29.....	162
Excerpt 5.30.....	163
Excerpt 5.31.....	163
Excerpt 5.32.....	163
Excerpt 5.33.....	164
Excerpt 5.34.....	165
Excerpt 5.35.....	167
Excerpt 5.36.....	168
Excerpt 5.37.....	169
Excerpt 5.38.....	171
Excerpt 5.39.....	172
Excerpt 5.40.....	175

Excerpt 5.41.....	175
Excerpt 5.42.....	176
Excerpt 5.43.....	177
Excerpt 6.1.....	199
Excerpt 6.2.....	201
Excerpt 6.3.....	201
Excerpt 6.4.....	202
Excerpt 6.5.....	203
Excerpt 6.6.....	204
Excerpt 6.7.....	214
Excerpt 6.8.....	214
Excerpt 6.9.....	215
Excerpt 6.10.....	216
Excerpt 6.11.....	216
Excerpt 6.12.....	218
Excerpt 6.13.....	219
Excerpt 6.14.....	220
Excerpt 6.15.....	223
Excerpt 6.16.....	226
Excerpt 6.17.....	227
Excerpt 6.18.....	228
Excerpt 6.19.....	229
Excerpt 6.20.....	239
Excerpt 6.21.....	240
Excerpt 6.22.....	242
Excerpt 6.23.....	244
Excerpt 6.24.....	245
Excerpt 6.25.....	246
Excerpt 6.26.....	246
Excerpt 6.27.....	247
Excerpt 6.28.....	247
Excerpt 6.29.....	248
Excerpt 6.30.....	250
Excerpt 6.31.....	250
Excerpt 6.32.....	250
Excerpt 6.33.....	251
Excerpt 6.34.....	252
Excerpt 6.35.....	252
Excerpt 6.36.....	253
Excerpt 6.37.....	253

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CHAPTER ONE

INTRODUCTION

“If my husband can’t remember the word he wants to say, should I say it for him?” This question, asked not just about husbands but also about wives, mothers, fathers, siblings, became so very familiar when I worked as a speech-language pathologist with people affected by progressive disorders such as Alzheimer’s disease (AD). Yet in family conversations, many of us regularly draw on our shared history and intimate knowledge with another to fill in words when that person experiences a momentary word-finding problem. Does the question arise so frequently because, in the context of disorders such as Alzheimer’s disease, word-finding difficulty takes on new meaning as it acquires the status of symptom?

It is widely recognized that communication difficulties are a significant problem for family members of people with disorders such as AD (Orange, 1991; Powell, Hale, & Bayer, 1995; Savundranayagam, Hummert, & Montgomery, 2005). In the context of a session with a speech-language pathologist, the question “should I say the word...” can be taken as a request for procedural guidance from someone with expertise in understanding the effects of disease on language and communication. But there can be no unequivocal answer to such a question. Talk is the bedrock of social life, an integral part of human relationship. For family, the most fundamental of social groups, disruption to talk is disruption to family itself. Accommodations to such disruption also extend far beyond the surface flow of conversation: disease may be pervasive in everyday family

life, but it is only one strand in the complex weave of roles, relationships, and history that is continually renewed and reconstructed through members' talk.

For family members of a person with a progressive cognitive disorder, the question "should I say the word..." is just one of many that can arise as they try to accommodate to changes associated with the disease. Further, at times family members must answer such questions in each and every conversation that they have with their affected kin. This does not mean that they necessarily frame the question as "should I ..." and then make a decision. In conversation, if our partner appears to be at a loss for a word, we either say it or we do not. What is called for is not an answer but an action. Undoubtedly, different members of the same family will take different actions; indeed, the same family member will probably take different actions in different conversational circumstances. Sometimes, people's actions will seem right, sometimes not. The effects of those actions become part of the experience that they take into account the next time they need to act, but it does not give them a "right" answer. For family members, these questions represent ongoing dilemmas that are further complicated by the progressive nature of the disease, which is yet another part of the ever-changing landscape in which conversations take place.

In the diagnostic clinic where I worked, I was typically able to spend only one session with the person coming for assessment and one family member. My clinician's perspective certainly gave me some basis for answering that person's questions: it was a perspective that was informed by my knowledge of the effects of progressive disease on language, grounded in the assessment results for that individual, and enriched by an understanding of the structure, flow, and goals of conversation in general. But at the

same time, I was becoming uncomfortably aware of just how little understanding I had about how families actually managed their everyday conversations with a relative with a progressive disorder such as AD. Ever more often I found myself asking the central questions that motivated this study: how *do* members of a family enact their answers to questions such as “should I say the word....” in their everyday interactions? More importantly, what do these answers mean, both for them as individuals and for the family as a whole?

A basic research premise underlying this study is that, although family members’ answers may be variable, they are never arbitrary. They shape, and are shaped by, meanings of disease, of family life, of conversation itself. By exploring, through their talk, how family members enact answers to questions such as “should I say the word...”, we can learn something about the dilemmas, challenges, and strategies comprised in that family’s process of coming to terms with a disease associated with progressive cognitive decline.

It is critical that we attend to family voices and family experience if we hope to offer meaningful, effective interventions to alleviate disruption associated with disease. Currently, Alzheimer’s disease and related disorders are situated as diagnostic entities in a biomedical world within which the voices of clinicians are authoritative, privileged, and, for the most part, respected. Biomedical descriptions of these disorders focus on progressive impairments and losses, which then form the basis for defining problems to be addressed. For family members interacting with the health care world, this view can dominate and shape their own experiences of the disease (Kitwood & Bredin, 1992; Lyman, 1989; Smith; 2000). Yet there is a growing body of literature to suggest that

when we listen to the voices of those who live with the disease, we find not only more relevant framings of the problems that we seek to address but also evidence of the expertise, creativity, and wisdom that individuals bring to the task of addressing those problems themselves (Davis, 2005b; Hamilton, 1994; Hoffman, 1994; Lyman, 1998; Perry, 2002; Phinney & Chesla, 2003; Sabat, 2001). This study, with its focus on family conversations, is a contribution to that literature.

Overview of the Study

Throughout the preceding discussion, I have referred to Alzheimer's disease as one of several disorders associated with progressive cognitive decline. While it is the most common of these, the recent evolution of new diagnostic categories (Neary et al., 1998) has led to a growing population of individuals diagnosed with what might be loosely termed "related disorders". Two families participated in this study, one with Alzheimer's disease, and the other with progressive aphasia. In Chapter Two, I begin with a review of the literature that formed the basis for the decision to include both disorders, including a discussion of how diagnostic categories are constructed in different discourses. I then move on to a discussion of relevant literature about family and conversation in the context of progressive cognitive decline. While there have been relatively few studies about conversations in families with AD (and none, to my knowledge, about families with progressive aphasia), there is a substantial literature that has contextualized and informed the present study. The chapter closes with a specific statement of the research goals.

Chapter Three begins with a description of the theoretical orientations that guided my research, followed by a brief discussion of case study methodology. It then provides a detailed description of study procedures to the extent that I could envision them without the input of the participants themselves. Two families agreed to participate in the study and together we designed specific procedures for data collection, arranged for ongoing contact, and negotiated ethical issues. In Chapter Four, I introduce the findings with a description of each of the two families who participated in the study, a summary of how we addressed issues that came up in the course of the study, and a description of the contexts in which interviews and conversational data were recorded. As each family was considered as a separate case, each of the following two chapters is dedicated to an interpretive description of the findings for that family. Each chapter closes with a short commentary that highlights and integrates key findings for that family. Finally, in Chapter Seven I move to a discussion that integrates findings from both cases, considering their significance in the context of the relevant research literature. The chapter concludes with a discussion of limitations of the study, a summary of lessons learned and their implications and, finally, with new questions arising from this research.

CHAPTER TWO

REVIEW OF THE LITERATURE

The objective of this chapter is to provide a framework within which the research question can be refined further. Two main topic areas will be explored: first, Alzheimer's disease (AD) and the related disorder of progressive aphasia and second, family experiences of AD. In the discussion of these topics, particular attention will be given to studies of language, communication, and conversation.

Constructions of Disease and Diagnoses

Within the biomedical framework of clinical practice, Alzheimer's disease (AD) is defined as a diagnostic category describing a specific form of dementia, characterized by progressive cognitive decline (APA, 1994). Alzheimer's disease, however, is more than a clinical diagnostic category. It is also part of a public discourse in which it is characterized in predominantly negative terms, such as "the loss of self" (Cohen & Eisdorfer, 1986) and "the vanishing" (Lambert, Armstrong, & Wagner, 1995, cited in Smith, 2000). These different representations invite attention both to the ways in which different meanings of Alzheimer's disease are constructed and, also, to the implications of those meanings. I begin the discussion with a brief history of AD as a diagnostic category over the past century, including a discussion of how there came to be a powerful public discourse associated with it. I then describe the ongoing evolution of AD as a biomedical construct, with particular attention to how language changes have been characterized as symptomatology, and of how further refinements in the diagnostic

process have contributed to new understandings of dementia and to new diagnostic categories. In the next section, I describe challenges to this predominantly biomedical view, including alternative views of the communication changes associated with AD.

The Emergence of Alzheimer's Disease as Diagnostic Category

The first documented case of Alzheimer's disease was Alois Alzheimer's published description of the post-mortem findings of a 51-year old woman, Auguste D., in which he described neurofibrillary tangles, senile neuritic plaques, and arteriosclerotic changes. While Alzheimer identified these findings as unusual on the basis of the woman's age, it was Emil Kraepelin who, on the basis of this and five similar published cases, proposed in his 1910 textbook of psychiatry that they warranted a new diagnostic category (Maurer, Volk, & Gerbaldo, 2000). Because these neuropathological changes appeared similar to those identified in cases of senile dementia (SD), the designation of Alzheimer's disease as a separate category led to ongoing debate about the relationship of Alzheimer's disease to senescence, including the diagnostic category of senile dementia. Throughout much of the twentieth century, Alzheimer's disease was differentiated from senile dementia primarily on the basis of the age of onset, that is, before or after either 60 or 65 years of age (Fox, 1989); as such, it was relatively uncommon. In 1975, however, Katzman and Karasu (1975) recommended that senile dementia and Alzheimer's disease be included in the single diagnostic category of Alzheimer's disease. Katzman and Bick (2000) pointed out that the scientific basis for the elimination of age as a criterion of differentiation was largely due to the pioneering independent work of Kidd and Terry with the newly developed electron microscope; their findings provided evidence in support of claims that the neuropathology of senile dementia and Alzheimer's disease

were the same. Fox (2000) noted that a second important factor underlying Katzman's and Karasu's 1975 recommendation was their observation that senile dementia was the fourth or fifth leading cause of death in the United States.

The redesignation of the two diagnostic categories of senile dementia and AD as one disease constituted a significant turning point in the concept of Alzheimer's disease in the latter part of the twentieth century. Fox (1989) quoted Katzman as claiming that of the 115 papers that he had published, the 1975 paper that he coauthored with Karasu was in his view the most important. Scientific discovery alone, however, could not account for the shift in thinking about AD. Holstein (2000) linked the debate around Alzheimer's disease and senile dementia to a conceptual shift in cultural views on aging, illustrating how disease categories are negotiated: what is significant is influenced by its cultural, social, and political context. She described how, by the late nineteenth century, growing old itself was viewed primarily as "an almost unrelenting pattern of decay in which the line between the normal and the pathological was quite indistinct" (p. 161). The label of senile dementia itself "contained an implicit etiology – that is, the very processes of growing old 'caused' the dementia." (p. 165). This negative view of aging persisted well into the second half of the twentieth century but, with the emergence of gerontology and geriatrics as fields of study, the view of aging as inevitable decline began to change. This change, according to Holstein, became part of a new interpretive horizon, thus contributing to shifting views of AD and SD, which "cannot be explained solely by the processes of scientific discovery" (p. 175).

The Emergence of Alzheimer's Disease in Public Discourse

The reconceptualization of Alzheimer's disease as a diagnostic category led to the development of a social movement (notably, the rise of the Alzheimer's Association in the United States, with similar organizations in other countries) around the phenomenon of Alzheimer's disease, in part because the merging of these two diagnostic categories immediately shifted the status of AD from that of a relatively rare condition to that of a major public health problem. In the United States, it also provided the newly established National Institute on Aging with a disease focus to facilitate the securing of research funding (Fox, 2000). Because AD was linked with aging, its prevalence was predicted to increase along with projected increases in the elderly population. Just as the "overselling of population aging" has been invoked as a way to influence social policy (Gee & Gutman, 2000), so too has the predicted increase in AD been used as an argument in support of increased funding and resources (Fox, 2000; Robertson, 1990); indeed, federal funding for research on dementing conditions in the United States increased from \$3.9 million in 1976 to an estimated \$67 million in 1987 (U.S. Congress OTA, 1987). Robertson (1990) pointed out that one of the consequences of this "catastrophic" view of population shift was the growth of a new sector of health care enterprise that in itself risks creating structured dependence of the elderly. The 1987 U.S. Congress report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, exemplified this view, noting that "professional recognition of the problems posed by dementia is also reflected in (and partly caused by) increased federal funding for biomedical research and training" (U.S. Congress OTA, 1987, p. 4) and citing the concern of policymakers faced with the increasing costs of dealing with dementias. As

Lyman (1989) suggested, “the ‘discovery’ of Alzheimer’s disease has involved a political process more than simply biomedical discovery” (p. 597).

The concept of Alzheimer’s disease found a place not only in the discourse of public policy, but also in media and popular culture. By 1987, it had “risen from relative obscurity to the cover of *Newsweek* magazine, the pages of *Life*, and prime-time television (‘Do You Remember Love?’ a made-for-television movie aired by CBS in May 1985)” (U.S. Congress OTA, 1987, p. 3). In the intervening two decades, it has continued to occupy a cultural niche, in fiction (e.g., *Scar Tissue*, Ignatieff, 1993), *If I were Me*, Blaise, 1997), film (e.g., *Iris*, Eyre, 2001; *The Notebook*, Harris, Johnson & Cassavetes, 2004) and popular music (*L’Oubli*, Rivard, 1992). Testimonies of high profile individuals diagnosed with AD and their families, including Rita Hayworth and Ronald Reagan, have contributed to a conceptualization of a disease that threatens all and, potentially, spares none. Post (2000) has linked the reconceptualization and prominence of Alzheimer’s disease to a hypercognitive society, arguing that the threshold of discontinuity that is implied in diagnosis “separates ‘them’ from ‘us’ and shields us from the fact that we are all a little demented by age 70” (p. 248). It is linked also with a cultural shift to more positive views on aging, particularly in contemporary consumer culture that, with its promise of rejuvenatory practices, further stigmatizes illness and decline (Blaikie, 1999).

While AD is portrayed clinically as inevitable loss of function, it is portrayed publicly as inevitable loss of person. The popular rhetoric of Alzheimer’s is powerful and overwhelmingly negative with its metaphors of vanishing, the long goodbye, the funeral without end (Smith, 2000). The Cartesian dichotomy of mind-body, with

supremacy given to mind in the oft-repeated statement “I think, therefore I am” is reflected in these metaphors, and emphasized in the designation of Alzheimer’s as “the loss of self” (Cohen & Eisdorfer, 1986). Hoffman, in a documentary film about her relationship with her mother who was diagnosed with AD, summarized her own reaction to the news of her mother’s diagnosis:

By this time Alzheimer’s was a sort of popular disease. I had heard a lot about it, and I had heard the grimmest and most depressing things of people you see lying in fetal positions and just unable to talk and feed themselves – and of course she was nothing like that but suddenly it dawned on me. I guess that’s where we’re headed (Hoffman, 1994).

Diagnoses may be made in the context of biomedically derived clinical practices, but they are interpreted in a broader sociocultural context with its own constructions of the meanings associated with disease. Hoffman’s description of her reaction emphasizes how the diagnosis, intersecting with popular representations, reframed her view of her mother as she projected for her a future of inevitable loss and decline. It also implies a diagnostic entity that is both homogeneous and predictable. To explore this further, I return now to consideration of AD as a diagnostic category, focusing on how it has evolved since it was first proposed in 1975.

Biomedical Descriptions of AD and Related Disorders

Since 1975, extensive biomedical study of Alzheimer’s disease, prompted in part by the search for effective pharmacological interventions, has led both to refinements of the diagnostic category of AD and to the identification of related but distinct diagnostic categories. These include, for example, Lewy body disease and frontotemporal lobar dementias (Neary et al., 1998).

The Evolution of Alzheimer's Disease as a Diagnostic Category

As senile dementia has been redefined as Alzheimer's disease, it has come to be viewed as a disease evidenced by the presence of neuropathological findings, rather than as a condition and consequence of aging. This focus on disease necessitated a standardized set of diagnostic criteria to support both the diagnosis as a construct and the epidemiological predictions that were based on it.

The development of standardized criteria.

It is widely acknowledged that the first set of proposed criteria came from the American Psychiatric Association in its third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III, APA, 1980) and the more recent DSM-IV (APA, 1994). These criteria specify that individuals with dementia of the Alzheimer's type must display a dementia of insidious onset with progressively deteriorating course, with other specific causes of dementia excluded by histological examinations. In 1984, McKhann and colleagues, working under the auspices of the National Institute of Neurological and Communicative Diseases (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA), developed criteria that differentiated probable AD from possible AD, intended to reflect the degree of certainty of the diagnosis and the possible presence of a secondary pathology. This refinement of existing criteria was prompted by findings that 20% or more of cases clinically diagnosed with AD were found at autopsy to have other conditions and not AD (McKhann et al., 1984). A diagnosis of probable dementia indicates the presence of a progressive dementia of insidious onset affecting memory and two or more other cognitive areas, including language (aphasia), motor skills (apraxia) and/or perception (agnosia); supported by impaired activities of daily living and altered

behaviour patterns; and confirmed by history and neuropsychological examination, in the absence of any other systemic or brain disease that would account for the deficits. A diagnosis of possible dementia is made when there is atypical presentation or when there is a secondary pathology that could in part account for symptomatology. A diagnosis of Alzheimer's disease can be confirmed as definite only when a patient has met the clinical criteria for probable Alzheimer's disease and histopathologic evidence consistent with the neuropathology of AD has been obtained from a biopsy or autopsy. The NINCDS-ADRDA criteria also acknowledged the possibility of subtypes that could be associated with features such as familial occurrence, onset before age 65, presence of trisomy 21, and coexistence of other relevant condition such as Parkinson's disease (McKhann et al., 1984, p. 940).

Staging and symptomatology of Alzheimer's disease.

Dillman (2000) observed that the concept of disease implicitly affects the way in which changes in patients are perceived: "differences between patients with AD and those considered to be normal ("controls"), are interpreted as the result of disease – that is a process that can be described as an existing object" (p. 147). In addition to prompting the development of standardized criteria for diagnosis, the designation of AD as a disease led to numerous descriptions of the symptomatology of the disorder. Some of these, while acknowledging variability, treated it as a homogeneous entity with identifiable stages, although these vary in different accounts from three (e.g., Cummings & Benson, 1983) to seven (Global Deterioration Scale; Reisberg, Ferris, deLeon, & Crook, 1982). While the former included stages of Alzheimer's disease only after diagnosis, describing them as early/mild, middle/moderate, and late/severe, the latter represented a continuum

in which there is no cognitive decline at the first stage, with the first clear-cut clinical evidence appearing only in stage three¹.

In the context of behaviour change as symptomatology, the hallmark feature of AD is impairment of memory systems and processes (Nebes, 1989), with most clinical observers agreeing that memory deficit is the most obvious early symptom of AD (Bayles & Kazniak, 1987). These authors, however, point out that communicative functioning also could show subtle deficits early in the course of the disease; additionally, word-finding problems have been sometimes identified as the first symptoms of AD, with memory impairment appearing later (McKhann et al., 1984). As the disease progresses, memory deficits, particularly for more recent events, become more severe (Bayles & Kazniak, 1987) with patients experiencing increasing difficulty in social and occupational functioning. Personality and behaviour changes associated with disease progression, including irritability, agitation, reduced responsiveness, and egocentricity have been described (Morris & Rubin, 1991). Later stages are characterized by more severe impairments of communication, praxis, and perception, with somatic and neurologic abnormalities such as incontinence, immobility, and abnormal reflexes eventually appearing (Reisberg et al., 1982; Bayles & Kazniak, 1987).

Language and communication changes, including characteristics of discourse, also have been described as part of the symptomatology of AD (Bayles & Kazniak, 1987; Kempler, 1991; Orange & Purves, 1996). Kempler (1991) and Bayles, Tomoeda, and Trösset (1992) described the language and communication changes associated with the

¹ In constructing cognitive decline along a continuum from no impairment to very severe, the Global Deterioration Scale (GDS) maintains a link between aging and Alzheimer's disease; the nature of that link, which is to some extent obscured by current conceptualizations of AD, continues to be contested (Dillman, 2000).

progression of AD across a three-stage continuum. Early stage deficits are characterized by impairments of word-finding, including an increasing reliance on semantically empty referents (e.g., *thing*, *stuff*). While morphosyntactic abilities were generally thought to be well-preserved (Kempler, Curtiss, & Jackson, 1987, Schwartz, Marin, & Saffran, 1979; Whitaker, 1976), more recent evidence has suggested that this may be an oversimplification and that impairments for more complex processes of sentence comprehension can be observed (Altmann, Kempler, & Andersen, 2001; Rochon, Waters, & Caplan, 1994; Small, 1997). Also, there is evidence that comprehension of more abstract, figurative language may be impaired even relatively early in the disease (Kempler, 1991; Kempler, Van Lancker, & Read, 1988). Bayles et al. (1992) differentiated language features of form, content, and use, suggesting that the first two were relatively spared in early AD, while language use in conversation could show evidence of impairment. Kempler (1991) identified such impairments as difficulty in following complex conversation, topic digression, and a tendency for individuals with AD to repeat themselves. Others too have identified problems of language use, including impairments of cohesion and coherence (Ripich & Terrell, 1988), changes in speech act and turn taking behaviour (Ripich, Vertes, Whitehouse, Fulton, & Ekelman, 1991), reduced topic management abilities (Garcia & Joannette, 1997, Mentis, Briggs-Whittaker, & Graminga, 1995), and increasingly empty speech as the disease progresses (Hutchinson & Jensen, 1980; Nicholas, Obler, Albert, & Helm-Estabrooks, 1985).

By middle (moderate) stages of the disease, increasing pragmatic deficits make conversations with people with AD ever more difficult to follow, (Hier, Hagen-Locker & Shindler, 1985; Kempler, 1991; Ulatowska & Bond-Chapman, 1991). Comprehension is

increasingly impaired and, although reading aloud and the mechanics of writing can be relatively well-preserved, coherent writing and reading comprehension typically are not (Kempler, 1991). By late stages of the disease, communicative abilities show considerable variability across individuals (Bayles & Kazniak, 1987); however, these abilities can be eroded to a point where verbal output is unintelligible because of paraphasias, lack of coherence, and/or dysarthria; ultimately, patients can become mute. At this point, comprehension can be impaired across all modalities, and the individual is no longer able to socially interact through communicative modalities (Kempler, 1991).

These characterizations of language and communication changes associated with AD across the course of the disease exemplify the identification of behaviours interpreted as the symptomatology of AD. Such interpretation necessarily focuses on impairments of the diagnosed individual, attributing changes to the disease. The standardization of experimental investigations of language changes in AD and of clinical assessment protocols typically seek to minimize or neutralize the effects of context in which the assessment takes place. For accounts of symptomatology to hold, individual variability must be explained, either in terms of other properties of the individual, or as indications of variability in the disease itself.

Further shifts in the evolution of AD as a diagnostic category.

The detailed descriptions and accounts of the presentation, course, and symptomatology of AD over the past three decades have resulted in widespread acknowledgement of individual variability, of alternative explanations, and of the possibility of different subtypes and/or subgroups (e.g., McKhann et al., 1984, Bayles & Kazniak, 1987, Martin, 1990). Over the past two decades, considerable attention has

been given to the question of subtypes. Blennow, Wallin, and Gottfries (1994) acknowledged that "for scientific studies as well as treatment trials, it is important to have homogeneous groups" (p. 102). However, they pointed out that because the NINCDS-ADRDA and DSM criteria for diagnosis were primarily through exclusion, heterogeneity of symptomatology was not generally considered in diagnosis. On the basis of their review of clinical symptomatology, they suggested a distinction between two subtypes of AD, differentiated on the basis of severity of temporoparietal symptoms, age of onset, vascular factors, and brain imaging. The differentiation of subtypes was extended to include familial AD in a later paper on the basis of genetic findings; these further differentiated between chromosome-1 linked familial AD and chromosome-21 linked familial AD (Sjögren, Wallin, & Blennow, 2003). Similarly, Lopez et al. (2000), on the basis of nearly two decades of research in a clinic diagnosing AD, found heterogeneity in both the course and presentation of individuals diagnosed with probable AD; they concluded that differences in presentation and course of AD could not always be attributed to secondary pathology.

Close attention to differences in patient groups has led, not just to reconsiderations of AD as a diagnostic category, but also to more systematically refined differentiations of other diagnostic categories associated with dementia. Differences across these diagnostic categories challenge a view of dementia as the erosion of cognition, a view that, according to Snowden, Neary, and Mann (1996) is grounded in global measures of intelligence. Instead, these disorders, subsumed in the category of fronto-temporal lobar degeneration, highlight patterns of focal decline. The extent to which these different patterns represent different diseases is disputed although, as in the

case of AD fourteen years earlier, a working group has proposed consensus guidelines to facilitate diagnosis (Neary et al., 1998).

Diagnoses of the non-Alzheimer's focal dementias are often made in clinics that are associated with the diagnosis of AD; often, they are made as a differential diagnosis from AD. One of these, primary progressive aphasia, is of particular interest, in part because it, like some cases of AD, can first manifest as difficulty with word-finding.

Progressive Aphasia

Aphasia of progressive severity has long been recognized as a component of cognitive decline, co-occurring with deterioration in behaviour and other cognitive domains such as memory and attention. However, Mesulam (1982) reported six cases in which progressive aphasia was present for several years in the absence of other cognitive decline, suggesting the possibility of a focal degenerative disorder specific to the perisylvian region of the left hemisphere. In a subsequent paper, Mesulam (1987) proposed that the condition be called "primary progressive aphasia" (PPA), emphasizing the disproportionate severity of language impairment throughout the course of the disease.

With numerous new cases reported over the past two decades, there has been considerable variability in descriptions of characteristics and evolution of PPA, leading to questions concerning its status as a distinct diagnostic category (Snowden, Neary, Mann, Goulding, & Testa, 1992; Snowden et al., 1996). Weintraub, Rubin, & Mesulam (1990) pointed out that PPA refers to a clinical syndrome (as does probable Alzheimer's disease), in contrast to neuropathologically-based diagnoses such as definite Alzheimer disease, with its characteristic neurofibrillary tangles and senile plaques, and Pick's

disease, marked by the presence of Pick's cells and bodies. They noted that autopsy findings for patients diagnosed with PPA have identified pathologies associated with Pick's disease, lobar atrophy, and Alzheimer disease, raising the question of the relationship of the clinical syndrome to an underlying pathology. In an extensive review of the relationship of PPA to Pick's disease, Snowden et al. (1996) discussed the nosological confusion resulting from applying the same label to different "levels" of analysis, including clinical and macro- and micro-pathology findings. They point out that, while Arnold Pick himself described clinical syndromes, including progressive aphasia, associated with atrophy of the frontal and temporal lobes, it was Alzheimer in 1911 who identified the histological changes that have come to bear Pick's name. However, neuropathological evidence from their own and other studies have led Snowden et al. to conclude that Pick bodies are not found at autopsy in many cases of fronto-temporal lobar atrophy (including PPA) which, in contrast, demonstrate a spongiform histology. They suggest that, for some authors, the presence of atrophy in the context of the clinical syndrome would be sufficient for a diagnosis of Pick's disease whereas, for others, the absence of the characteristic histological changes would preclude such a diagnosis. They conclude that at present it is not possible to predict the type of histological changes on the basis of clinical syndromes, nor is it possible to determine whether the histological differences are etiologically distinct. They emphasize at the same time the importance of clearly differentiating between levels of analysis in description if these questions are ever to be satisfactorily resolved.

Clinical characteristics.

While the underlying pathology (or pathologies) associated with PPA remains problematic, the clinical characteristics associated with the disorder also have been subject to debate. Both nonfluent and fluent forms of PPA have been described, with some authors suggesting the possibility of different subtypes (Snowden et al., 1992; Mesulam, 2001). Although Snowden et al., on the basis of a longitudinal study of sixteen patients with progressive language disturbance, suggested the possibility of three profiles of progressive aphasia including both fluent and nonfluent forms, in subsequent work (Snowden et al., 1996) they identified three distinct but related syndromes, each with its own characteristic profile of language deterioration. These include fronto-temporal dementia, nonfluent progressive aphasia (PA), and semantic dementia. Despite a consensus statement on differential diagnosis (Neary et al., 1998), inconsistencies remain in the literature. For instance, Kertesz, Davidson, McCabe, Takagi, and Munoz (2003) point out that the fluent/nonfluent distinction is problematic for a number of reasons in descriptions of PPA. First, they suggest that it has been confounded by comparing reports in which patients are examined at different stages of illness. Their own longitudinal study of 67 patients with PPA indicates that most individuals present initially with anomia and relatively preserved fluency, with loss of fluency developing at later stages of the disorder. Second, fluency is a multidimensional construct which traditionally encompasses ratings of prosody, grammaticality, and articulatory effort (cf. Goodglass, Kaplan, & Barresi, 2001) leading to differing definitions of fluent versus nonfluent production. For example, whereas Thompson, Ballard, Tait, Weintraub, and Mesulam (1997) described four cases of nonfluent PPA, three of which presented with

agrammatism and one of which was characterized by hesitancy and incomplete utterances attributed to word-finding difficulties with relative preservation of grammatical abilities, Orange, Kertesz, and Peacock (1998) cite these findings as reflecting nonfluent and fluent forms of PPA respectively.

Although both fluent and nonfluent subtypes of PPA have been reported, it can be argued that nonfluent PPA is the prototypical presentation (Karbe, Kertesz, & Polk, 1993; Kempler et al., 1990; Weintraub et al., 1990) with fluency relatively well-preserved in early stages. Loss of fluency has repeatedly been reported as a characteristic feature differentiating PPA from AD (Kertesz et al, 2003; Snowden et al., 1996; Mesulam, 2001, 2003; Northen, Hopcutt, & Griffiths, 1990; Weintraub et al., 1990). In contrast, in considering fluent forms of PPA, it has been suggested that these are atypical presentations of AD in which progressive aphasia is the initial symptom; for this reason, Weintraub et al. (1990) have suggested that a period of at least two years during which language impairment is unaccompanied by other cognitive or behavioural changes would lead to more reliable differentiation from such atypical presentations of Alzheimer disease, a criterion which has come to be widely accepted in operational definitions of PPA (Mesulam, 2003).

Symptomatology of nonfluent progressive aphasia.

According to Neary et al.'s (1998) consensus report, the core language characteristics of nonfluent PPA include: nonfluent spontaneous speech with at least one of the following: agrammatism, phonemic paraphasias, anomia. Supportive diagnostic features include: stuttering or oral apraxia, impaired repetition, alexia, agraphia, early preservation of word meaning, and late mutism. Behaviour is characterized by early

preservation of social skills, but in late stages of the disease, changes similar to those found in fronto-temporal dementia are seen. Further descriptions of nonfluent PPA have addressed pragmatic performance, differentiating it from that seen in frontal lobe dementia and fluent PPA (Orange, Kertesz, et al., 1998) and characterized by inappropriate use of topic maintenance skills, off-topic comments, poor response to partner's questions and requests, poor use of reference, and limited contributions to semantic development of topics. In addition, subjects with nonfluent PPA appeared to be less aware of their linguistic and pragmatic difficulties than were the subjects with fluent PPA. These findings are somewhat surprising, in light of descriptions elsewhere (e.g., Snowden et al., 1996) that suggest relatively preserved insight and awareness of deficits in individuals with non-fluent PPA. However, a review of subjects' scores on the Western Aphasia Battery suggested that the nonfluent subjects were significantly more impaired overall than those with fluent PPA. Given that no data are given with respect to time since diagnosis, nor with respect to relative impairment of comprehension, and, in light of Kertesz et al.'s (2003) subsequent findings that fluency may be preserved in early stages of nonfluent PPA, the possibility that the pragmatic differences seen in this study reflect quantitative differences in severity, rather than qualitative differences in type, must be considered.

Disease progression and outcomes.

Although some studies have found that language impairment can progress with relative sparing of other cognitive and behavioural abilities for much longer than two years (Mesulam, 1982; Kesler, Artzy, Yaretzky, & Kott, 1995; Kempler et al., 1990), there is general consensus that the syndrome more typically evolves to include other

cognitive and behavioural domains (Neary et al., 1998; Snowden et al., 1996). The relative frequency of evolution to include the behavioural abnormalities of fronto-temporal dementia (FTD) has been cited as evidence that these syndromes, though neuroanatomically distinct, are related manifestations of the same disease process (Snowden et al., 1996). In a longitudinal study of 67 patients, Kertesz et al. (2003) reported that 25 patients developed FTD, 15 developed corticobasilar degeneration, and 8 developed symptoms of both conditions.

Alternative Constructions of Alzheimer's Disease and Progressive Aphasia

Diagnosis of Disease and the Experience of Illness

Descriptions and accounts of the presentation, course, and symptomatology of both Alzheimer's disease and progressive aphasia reveal how diagnostic categories are both framed and contested in biomedical discourses. Nonetheless, the designation of these disorders as single disease entities minimizes the distinctions and differentiations that underlie contested categories, particularly when we move from consideration of Alzheimer's disease and progressive aphasia as abstract categories to considerations of them as illness; my use of the term illness here reflects Kleinman's (1988) definition, that is, as the subjective experience of the sufferer. A diagnostic category forms a useful conceptual framework to guide further questions and understandings of disease constructs, but it takes on different meanings in the lifeworld of the person to whom it is applied (Cicourel, 1993). In the clinical world of diagnostic categories, progressive aphasia and Alzheimer's disease are different but related within the broader category of cognitive decline. In the sociocultural world of people diagnosed with these disorders,

however, they are vastly different. In contrast to Alzheimer's, the term progressive aphasia is not found in the discourses of popular culture or public policy. Nevertheless, people diagnosed with progressive aphasia, like those diagnosed with Alzheimer's disease, are faced with the task of constructing meanings around the diagnosis.

In the case of Alzheimer's disease, the categories of probable and possible AD are semantic reflections of the uncertainty of clinical diagnosis in its reliance on observed and reported behavioural symptomatology. Yet, in efforts to define more precisely the behavioural symptoms associated with AD as disease, researchers and clinicians have created generic descriptions with identifiable stages and a seemingly predictable course: Alzheimer's attains certainty, and takes on explanatory power. Diagnosis, particularly for family members, offers a way to restore intersubjective order when this is threatened by increasing difficulty in participating with the affected individual in expected and familiar ways (Smith, 2000; Robinson, Ekman, & Wahlund, 1998). It also offers a means of legitimizing responses to perceived changes (Hanson, 1991, 1997; Smith, 2000) and to prepare for the future (Clare, 2002; Gwyther, 1997). At the same time, uncertainty associated with diagnoses qualified as probable or possible can lead to differences in how family members interpret a diagnosis, either accepting or rejecting the diagnosis depending on whether it is congruent or not with their own explanations of behaviour changes (Smith, 2000; Smith & Kobayashi, 2002). Ironically, in the biomedical world of refined diagnoses, a diagnosis of probable AD made according to NINCDS-ADRDA criteria suggests that confirmation is likely in approximately 95% of cases (Lopez et al., 2000), but in the lay world, "probable" can be interpreted as "maybe not." This ambiguity itself can result in even more uncertainty for family (Garwick, Detzner, & Boss, 1994),

leading to a recommendation that the qualifications of probable or possible AD be omitted in disclosing diagnoses to families (Smith & Beattie, 2001).

Lyman (1989) pointed out that the staging of Alzheimer's disease (i.e., the description of identifiable stages in the course of the disease) may help to provide a sense of predictable trajectory to a disease portrayed as inevitable decline: "If the illness can be defined as having a beginning and middle, the end may be predicted" (p. 599). At the same time, there is an inherent tension when the representation of AD as a homogeneous, staged progression is at odds with the experience of those affected. Gubrium (1987) illustrated how the staging of AD is both structured and destructured in interaction, describing an AD caregivers' support group in which group members, including the group leader, both supported and contested the descriptions of stages when talking about their kin. It is common for clinicians to acknowledge and even highlight how descriptions of stages do not necessarily describe or predict the course of disease for a particular individual, while at the same time reifying the descriptions in presenting them.

In the case of progressive aphasia, the comparative recency of its emergence as a diagnostic category, its relative rarity, and its less predictable course present very different challenges to those seeking to understand the implications of a diagnosis. In contrast to the widely available literature and information about Alzheimer's through well-established organizations at, typically, local, regional, and national levels, information about progressive aphasia is available mainly through websites sponsored either by support groups or associations for other, related diagnostic categories (e.g., Alzheimer Society of Canada, Pick's Disease Support Group, National Aphasia Association, Aphasia Hope Association); only one website is dedicated specifically to

primary progressive aphasia (www.brain.northwestern.edu/ppa sponsored through Northwestern University). Contextualizing the information within these different diagnostic groups itself contributes to uncertainty around the diagnosis. This uncertainty is reflected in email exchanges of on-line support group members or individuals contacting on-line information services, exemplified in the following:

I'm looking for as much help as possible in determining the treatment for these two diseases [progressive aphasia and Pick's disease]. We visited a neurologist yesterday with regard to my mother who was diagnosed with either of the two. We have additional tests scheduled to more clearly establish the problem. Can anyone comment on the following questions: Can this be reversed? How does this end? How long can things be stabilized for? I haven't resolved myself to the fact that this is not stoppable, my sister and I, and my whole family want the old Rebecca back, how do we make this happen?

(sonofrebecca, 2004).

My dad was recently diagnosed with Primary Progressive Aphasia. He didn't have a stroke because my mom had him get a CAT scan and they said he didn't have a stroke. It just suddenly happened. He did have a toothache and had it pulled around the same time but not sure that would cause it. Since we don't have a cause, friends and family are not sure about the diagnosis. Can it come about this way?

(Jane, 2003).

Primary progressive aphasia and Alzheimer's disease, then, are differentiated not only as diagnostic categories representing different diseases, but also in the meanings attached to those categories through other public discourses.

To the extent that a diagnostic category offers the possibility, however illusory, of predictability and explanatory power, it risks neglecting other explanations that could alter both expectations and outcomes. In recent years, there have been a growing number of challenges to the predominantly biomedical construction of dementia; this has been particularly apparent in the case of Alzheimer's disease. These challenges draw attention to alternative ways in which behaviours typically associated with disease and its

symptomatology can be constructed and, further, to the implications of those competing constructions for our regard and care of those diagnosed with AD or other forms of dementia.

Alzheimer's Disease and Social Interaction

Kitwood (1990, 1997; Kitwood & Bredin, 1992) argued convincingly that the effects of AD can not be accounted for solely by its neuropathology. He pointed out that AD also is a social phenomenon informed by a public discourse of AD and shaped by one's interactions with the world. He suggested that the social stigma associated with AD can lead to a "malignant social psychology" (Kitwood, 1990, p. 183), in which the expectations and responses of those interacting with the person with AD can themselves lead to the undermining and decline, not only of that person's abilities but, ultimately, their personhood. In describing personhood, Kitwood (1997) suggested that its primary associations are with self-esteem; the place of the individual in a social group; the performance of given roles; and with the integrity, continuity and stability of the sense of self. His own definition of personhood is a "standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p.8). Personhood is situated in a social context, because it is less a property of the individual than it is a status provided through interaction with others.

Kitwood's emphasis on the central role of interaction in sustaining the personhood of individuals with dementia invites examination of the conversational interactions between those individuals and those who care for them. Despite acknowledgement of preserved abilities across the progression of AD (Hopper, Bayles, &

Kim, 2001; Orange & Purves, 1996), deficit-based descriptions of the communication abilities of those with AD have tended to predominate, leading to the possibility of lowered expectations on the part of interlocutors and ever fewer opportunities for interaction. Acknowledgement of this influence of malignant social psychology on conversations has led to a shift away from the communication abilities of the individual with AD to conversations in which the contributions of each interlocutor are seen as equally important in shaping the interaction. Sabat (1994), in a critical review of selected literature on language function in AD, pointed out that the language performance of individuals with AD is elicited often under experimental rather than naturalistic conditions. He criticized this approach on several grounds: first, these experimental conditions can mask remaining abilities, or at least fail to provide facilitation which could enhance them; second, the focus on deficits identified by group performance leads to a stereotypic picture of the person with AD that positions people with AD as defective, and, third, the description of language deficits in AD itself acquires the status of explanation, so that social-psychological dimensions that could be relevant are not explored. Hamilton (1994) made similar claims, pointing out that while the diagnostic procedures typically used in language assessment have some value for understanding particular aspects of the language of a person with AD, they offer little insight into the communicative abilities of that person. Such critiques have led to increasing advocacy for the study of communication abilities of people with AD within the context of naturally occurring conversations (e.g., Perkins, Whitworth, & Lesser, 1998).

Conversation analyses of interactions with people with cognitive impairments are increasingly well represented in the research literature (see, for example, Davis, 2005b;

Goodwin, 2003; Guendozi & Müller, 2006; Kovarsky, Duchan, & Maxwell, 1999). The underlying methodological assumption of analytic approaches such as conversation analysis (CA) and interactional sociolinguistics is that conversation is both collaborative and orderly (see Chapter Three for more comprehensive discussion); accordingly, they promote consideration of behaviours as jointly constructed adaptations to contextual circumstances, only one of which is cognitive impairment. In many of these studies, nevertheless, cognitive impairment is significant as a motivating factor in the conversation, that is, the person is identified as someone with AD, and the conversation partner is someone who has known them only since that diagnosis, either as researcher or as research participant (often graduate students)². The works of Sabat (1991a, 1991b, 1999, 2001), Sabat and Cagigas (1997), and Hamilton (1994) are significant contributions to an understanding of how the presentation and communicative abilities of individuals with AD are constructed in social interaction, highlighting the importance of the interlocutor in those constructions. Hamilton's (1994) account of her conversations over a four and a half year period with Elsie, a woman with AD, offers new insights into changes in communication previously described in terms of the staged progression of AD, situating these in the joint interaction between the person with AD and an interlocutor accommodating to perceived changes.

Studies of conversations encourage alternative interpretations of conversational behaviours that are otherwise described as symptoms, considering them rather as interactional adaptations of co-conversationalists to cognitive changes. For example,

² Exceptions to this are Small, Geldart, Gutman, & Scott (1998), Shenk (2005) and Ryan, Byrne, Spykerman, and Orange (2005) who also studied interactions between people with dementia and formal caregivers. In addition, there are studies of conversation between people with AD and family members; these will be discussed in the next section of this review.

discourse “problems” such as lengthy within-turn conversational pauses and repetitive questions have been reinterpreted in terms of their contribution to sustaining conversation (Brewer, 2005; Müller & Guendouzi, 2005). Finally, such studies draw attention to the way in which interlocutors make use of available conversational resources, such as discourse markers, repair strategies, and turn-taking conventions, to sustain interaction (Bohling, 1991; Davis, 2005a, Hamilton, 1994; Sabat, 1991; Watson, Chenery, & Carter, 1999; see Simmons-Mackie, 1993 for investigation of such resources as compensatory strategies for a woman with progressive aphasia).

Studies of conversations also have explored how individuals with AD and their conversation partners continue to construct and negotiate meanings of self and identity despite declining cognitive and conversational abilities. Sabat and Harré (1992), differentiating the personal self from the multiple personae of social selves, illustrated how both were constructed through conversations between Sabat and individuals with AD. Small, Geldart, Guttman, and Scott (1998), taking into consideration the interplay of internal (cognitive) and external (social) conditions, analyzed how the preservation of self-identity of nursing home residents with dementia was managed through conversations with staff. Ryan, Byrne, Spykerman, and Orange (2005) examined how Kitwood’s strategies for personhood were evidenced in a long term care setting in conversations between a man with AD, researchers, and formal caregivers. Studies of conversational narratives have informed our understanding of their role in maintaining identity and creating meaning for people with AD (Basting, 2001; Ramanathan-Abbott, 1997; Shenk, 2005).

The foregoing studies inform our understanding of the everyday experience of progressive cognitive decline, highlighting the constraints and accommodations that together shape the everyday conversations of people diagnosed with such conditions and their partners. Such insights are afforded by a perspective that acknowledges conversation to be both fundamentally interactive and highly contextualized, jointly constructed among participants in particular contexts. The following section explores further one of these particular contexts, that is, the family.

Alzheimer's Disease and the Family

Those who live with Alzheimer's disease and other disorders of progressive cognitive decline include not just those who are diagnosed with these diseases, but also other members of their social world, in particular, their family. The importance of studying the impact of AD and other dementias on family has long been recognized, acknowledging the key role that families play in caring for their affected kin (Pearlin, Harrington, Powell Lawton, Montgomery, & Zarit, 2001). A focus on family caregiving, including its impact on the family, has been motivated in part by considerations of how and when to best support family caregivers in keeping individuals with AD at home, versus placing them in institutional care (e.g., U.S. Congress OTA, 1987). Such concerns have situated the family's experience of AD primarily in the context of family care; there are, however, a number of studies, albeit relatively small, that have focused also on the family's experience from other perspectives (e.g., Blum, 1991; Orona, 1990; Garwick, Detzner, & Boss, 1994; Brewer, 2005). Nonetheless, the majority of studies of AD and related disorders have focused on family as caregivers. Many of these have characterized

caregiving in terms of stress and burden (e.g., Fisher & Lieberman, 1994; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit, Reever, & Bach-Peterson, 1980), seeking to identify factors that mediate and mitigate these negative correlates of caregiving. Gubrium (1991) has described such studies in terms of "the caregiving equation" (p 50), arguing that while these studies have identified the complexity of interactions of factors in family caregiving, the linearity of reasoning underlying this approach has obscured the meanings of those interacting factors. In contrast, he pointed to a growing number of studies that have explored the complexity of caring by qualitative study of "the care experience" (p. 53). The following discussion focuses on studies in this latter category, that is, those that focus on families' experience of AD and similar disorders, including, first, who family is and, second, the nature of family caregiving.

The Concept of Family Caregiving

Who/What is Family?

Studies of families and diseases such as AD are not only differentiated by how they conceptually and methodologically approach their central questions. They also differ in their designations of family. Keating, Kerr, Warren, Grace, and Wertenberger (1994) identified several important differences among studies of the family experience of Alzheimer's disease. One such difference is whether the study examines family caregiving as care provided by one person who is a family member, or whether it is care provided by a group of people who are kin. A second difference concerns studies that purport to have family (i.e., a social group) as their focus, but of which only some include multiple family members to establish family as their unit of analysis. Other studies, in

contrast, may describe the family context of care but include the perspective of only individual, most often the primary caregiver, leading to serious questions about the extent to which they can be considered as studies of family.

While Keating et al.'s review highlights differences in how studies address the question of *who* is family, Gubrium and Holstein (1990) have addressed the broader question of *what* is family. They challenged assumptions that "the family" can be defined in any satisfactory a priori way, arguing that "family" is constructed through the discourse of individuals in their everyday lives; these constructions may or may not include people who are biologically related. If we are to understand the experience of people with dementia and their families, attention to the ways in which they construct those families is an integral part of that understanding. Accordingly, while some studies may consider non-kin as part of a broader social network in which individuals with AD and their families are situated, in others, they may emerge as part of family itself.

Who/What is a Caregiver?

Just as the concept of family invites closer attention, so too does the concept of caregiver. The term "family caregiver" has been used for decades in research literature; as an unqualified term, it implies a homogeneity in which gendered, generational, and other differences are overshadowed by the caregiver role. Assumptions of homogeneity have long been challenged, however. Acknowledgement of involvement of more than one family member in providing care has led to differentiation of primary caregivers as those who provide the majority of care from secondary caregivers as those who provide additional care (Tennstedt, McKinlay, & Sullivan, 1989). The importance of role relationships in family caregiving has been emphasized (Montgomery & Williams, 2001),

including gender and generational differences (Globberman, 1995, 1996; Keating et al., 1994; Matthews & Rosner, 1988), The importance of the sociocultural context of the family, including considerations of, for example, ethnicity has also been acknowledged (Dilworth-Anderson, 2001; Liu & Kendig, 2000).

While numerous studies have informed our understanding of *who* are the caregivers, both for people with dementia and, more generally, for the elderly, they have, for the most part, not explicitly addressed the question of *what* is a caregiver. Stone (1991) has pointed out how differences in definitions of family caregivers can have implications for public policy and support, highlighting some of the challenges in establishing definitions that can be widely accepted. Only recently, however, has the question of how and when family members designate themselves as caregivers been explored. O'Connor (2005) found in a qualitative interview study of forty-seven family members that they positioned themselves as caregivers primarily through interactions with others, including both health care professionals and members of support groups. Her analysis draws attention to the way in which the term "caregiver" itself is situated in a discourse that not only positions the individual to whom it applies, but also positions the person with dementia as care-recipient, a positioning necessitated by the dementia. O'Connor discussed both the benefits and risks of such positioning in the context of the care relationship. However, her findings have broader implications for our understanding of the experience of families with members diagnosed with AD, suggesting that the a priori designation of family members as caregivers contextualizes their experience within specific discourses in ways that may themselves bias the interpretation of findings. Kirs, Hervonen, and Jylhä (2000) for example, found that husbands in their written narratives

sometimes positioned themselves as laymen relative to the reader who, in a letter inviting the narratives described himself in terms that positioned him as a male, as a doctor with experience in caring for people with dementia, and as a professor with cultural competence and high social status.

The Study of Family Caregiving in AD

Individual Family Members as Caregivers

Studies of individual family members' experiences of dementia, even when not differentiated by role relations, have greatly informed our understanding of what it means to live with a family member with Alzheimer's disease. A significant theme in this body of research focuses on identity and the threats to identity associated with Alzheimer's in the context of family. Orona (1990), drawing on retrospective accounts of individuals who had cared for family members with AD in the 1970s, described "indicators of identity loss" (p. 1251), including the threat that these posed to perceived role relationships, as well as the ways in which family members strove to maintain markers of identity over time. Her study also highlighted temporal aspects of experience. These included not only how family members shifted their strategies to maintain identity over the time course of the disease, but also included how the sociocultural context of the 1970s, in which AD was not significantly represented in public discourse, influenced family members' experiences of the disease.

Since Orona's study, several others have explored how family members experience and cope with perceived changes in the identity of the person with AD. MacRae (2002), in a qualitative study of 53 family members, including husbands, wives,

sons and daughters of individuals with AD representing both primary and secondary caregivers, identified a number of strategies that family members employed to protect the social and self-identity of the person with AD. She concluded that for family members identity maintenance work is a key component of family caring; this may account in part for why family members can be reluctant to place their kin in institutions, where others may not be able to provide this critical component of care. Her findings are consistent with those of Perry and O'Connor (2002) who also described strategies of caregiving spouses for preserving the personhood of their partner with dementia. Chesla, Martinson, and Muwaswes (1994) found differences among family members, including wives, daughters, husbands, and sons, in how they experienced their relationship with the person with AD as the disease progressed. Three patterns of perceptions of relationship emerged: continuous, continuous but transformed, or radically discontinuous. Although they did not set out to identify patterns associated with particular role relationships, the authors commented that none of the twelve male participants experienced the first pattern (continuous relating) and that wives were predominant in that category. Although this finding could be specific to their sample, it also points again to the importance of specifying role relationships.

Attention to role relational differences among family members as caregivers has led to several studies that have further enriched our understanding of the experience of AD within families; although such studies focus on just one individual, that person is situated by his or her role in particular ways within the family. It is generally acknowledged that family caregivers are most often women; although husbands and sons participate in caregiving, they have been described typically as deferring to female family

members (Abel, 1990; Globerman, 1996; Matthews & Rosner, 1987). However, it also has been suggested that this gendered view of caregiving is oversimplified (Parsons, 1997) and risks diminishing the heterogeneity of caregiving among both male and female family members (Russell, 2001). Clearly, understanding of the meanings of caregiving in the context of different role relationships is critical. Studies focusing on caregiver meanings associated with particular roles offer insight into the person's experience, not just as caregiver, but also in terms of his or her long-standing relationship to the person with dementia; these include studies of wives caring for husbands (Brown & Alligood, 2004; Perry, 2002), husbands caring for wives (Kirsi, Hervonen, & Jylhä, 2000, 2004; Parsons, 1997; Russell, 2001; daughters caring for mothers (Perry, 2004), and daughters-in-law and sons-in-laws caring for their spouses' parents (Globerman, 1996). Review of a subset of these illustrates how they highlight dimensions of caregiving experiences associated with each group.

Perry (2002, 2004), in two qualitative studies of wives caring for husbands and daughters caring for mothers, found a cognitive dimension of that caring that allowed wives and daughters to recreate identities for both themselves and their kin in meaningful ways. This cognitive dimension moved caring from task-based to purpose-oriented activities, allowing for the acknowledgement of both positive and negative aspects of caring. While both groups engaged in strategies to sustain the personhood of their kin, Perry (2004) identified important differences. In contrast to wives with their greater day-to-day knowledge of husbands, daughters' strategies for supporting their mothers' personhood involved trying to imagine what their world was like. She also found that, whereas for wives' care for husbands was couple-oriented, supporting the spousal dyad

as a unit of family, daughters' care was linked to bonds with their mothers but also, more broadly, to family, sometimes with commitments to fathers.

Despite the acknowledged prevalence of women as caregivers, there is increasing attention to the experience of men as caregivers, particularly as husbands caring for wives. Parsons (1997) explored male experiences of caregiving in a phenomenological study that included both husbands and sons. She attributed eight themes that emerged, including enduring, vigilance, sense of loss, aloneness and loneliness, taking away, searching to discover, need for assistance and reciprocity, to both groups of male caregivers. However, one additional theme, overstepping the normal boundaries, emerged from the sons' data only, thus differentiating the two groups. Parsons linked this finding to sons' experiences in providing physical care that was not part of what was expected in a parent-son relationship.

Role relational differences among male caregivers may not be the only basis for heterogeneity in reported experiences of male caregivers. Russell (2001) cited Thompson's (1997) contention that there is a "feminine yardstick" of caregiving based on decades of research literature, in which men are judged to be deviant as caregivers if their caregiving differs from that of women, and deviant as men if it is the same (p. 354). He identified two theoretical perspectives that have emerged in the caregiving literature, one which postulates that the work of men is ineffective and inconsequential, and one which postulates that men are capable and competent caregivers, blending managerial with nurturing elements of care. He explored these further in a qualitative study of men giving care to their wives with dementia, finding that, despite their experience of isolation and doing invisible work, these men were capable, nurturing, and innovative carers who

exhibited commitment, adaptability, and resilience (p. 364). His findings were partially supported by Kirsi et al. (2004). who observed, however, that the ways in which husbands in their study described their competence were in part dependent on their audience (male or female interviewer, written narrative for a male professor/doctor with expertise caring for people with dementia and their caregivers), on the interviewers' actions in co-constructing talk, and on the activities they ascribed as part of their caregiving.

Two interrelated themes that emerge in accounts of individual family caregiving experiences reflect a broader theme in the caregiving literature, that is, the relative lack of support from other family members. Keating et al. (1994) cited an earlier study (Willoughby & Keating, 1991) which found that family members caring for individuals particularly in early stages of the disease frequently reported that they did not receive enough help from other family members. MacRae (2002) pointed out that one of the costs incurred by family members' covering up of symptoms was that it limited their ability to turn for help to others, including family members. Russell (2001) found that husbands' experiences of isolation and the invisibility of their care were linked with reports of other family members' unfulfilled promises of support. A study of couples coping with care of elderly parents identified the theme of inequity among siblings (reported from the perspective of one sibling), discussing strategies that emerged for coping with redressing perceived inequities, either by forging actual equity through increased involvement, or forging psychological equity by changing perceptions of what constituted equitable participation (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003). While these comments about family support are valuable in the context of understanding

the individual caregivers' experiences, they represent only one perspective. Furthermore, they imply a static view of family support which fails to account for the ways in which descriptions of that support may be contextualized. For example, Gubrium (1988) found in a study of support groups that any kinship network could be constructed as responsible against some standards and irresponsible against others. Nonetheless, they invite consideration of family experiences of caregiving to understand how individuals in a family work together (or not) in giving care to a member with AD.

Caregiving in the Family

Although the vast majority of studies of caregivers of people with AD have focused on that individual designated as primary caregiver, there are several studies that explore family experiences of AD, including how family members share responsibility. Among these are studies that focus on how adult siblings participate in caregiving for elderly parents (although not necessarily parents with AD), including pairs of sisters (Matthews & Rosner, 1988), of brothers, and of sisters and brothers (Matthews, 2002). Analysis of accounts from more than one sibling, including men, privileged neither, so that gendered differences emerging in caregiving experiences of brothers and sisters were not interpreted within an implicit framework that equates "best practice" with "women's practice." Furthermore, conflict between and among siblings was related to family structure (gender and number of siblings), because characteristics such as gender, distance from home, etc. were considered in relative, rather than absolute terms: congruent with Ingersoll et al.'s (2003) findings, conflict arose when there was failure to divide labour in accordance with these perceived relative attributes. These findings emphasized how attention to family networks leads to a shift in focus from family roles

to family relationships. Matthews (2002) argued that failure to consider such relationships could result in research findings that "are unlikely to provide an understanding of *actual* family life" (p. 212).

The importance of historical family relationships has been supported in several studies. Drawing on Erickson's (1959, 1982) developmental theory, Globerman (1994) described the experiences of six families participating in the care of a member with AD, finding that adult children felt consumed by their families of origin as they were expected to return to long-standing roles. However, adaptation to illness involved the negotiation of new roles, posing new challenges for the participants. For all family members involved in care, developmental tasks were suspended as they tried to maintain the family through what they perceived as an unpredictable, ever-changing crisis. In a later study, Globerman (1995) further explored the negotiation of responsibilities, identifying in some families the role of "unencumbered child." This term described individuals who, on the basis of long-standing relationships in the family, were excused from taking part in care; nevertheless, they too experienced a sense of loss and suffering, albeit differently from their more involved siblings.

Families' perceptions of the unpredictability of AD, as well as the negotiation of new roles necessitated by their accommodations to it have been found to be a significant feature of their experiences, leading to ambiguity about boundaries of the family as a system (Boss, 1993, 1999; Garwick et al., 1994). However, in both Globerman's (1994, 1996) and Garwick et al.'s (1994) studies, findings have been discussed across families, obscuring visibility of each family as an independent unit. In contrast, Le Navenec and Vonhof (1996) incorporated theoretical perspectives of boundary ambiguity theory,

symbolic interactionism, and family systems theory in a study of how thirty-nine families managed the experience of caring for a family member with dementia. On the basis of interviews with multiple members of each family over time, they identified several styles of managing. These styles reflect differences among families' characteristics (open versus closed) and orientations to care (e.g., solution versus comfort oriented), again emphasizing the heterogeneity of the caregiving experience.

Recognition of the family as a unit invites consideration of how the family collectively makes meaning of its circumstances, necessitating understanding of how these meanings are shared (or not) among individual members. Garwick et al. (1994) pointed out that in their study of thirty-eight families, a pattern of exclusion of family members made it difficult for families to talk together about the disease in collective interviews, presenting challenges to the families' abilities to construct shared meanings around Alzheimer's disease. Perry and Olshansky's (1996) study of five members of just one family, based on interviews with either individuals or subsets of individual members, illustrated how differences among individual meanings, which concerned the identity of the person with AD and the individual's relationship with that person, prevented the family from coming together to develop a unified coping strategy. The detailed description of individual views within the family facilitates understanding of interactions between individual and family levels of experience, highlighting how differences in the ways that individuals make meaning of new situations have consequences for the whole family.

While family history and relationships have been identified as important to an understanding of the experience of AD in families, so too have cultural values and belief

systems (Dilworth-Anderson, 2001; Liu & Kendig, 2000). Smith and Kobayashi (2002) described a Japanese-Canadian family's response to a diagnosis of Alzheimer's disease for the father, a second-generation Japanese-Canadian man). Family history and cultural values influenced individual attitudes, resulting in divergent interpretations of changes in the father that led to differences in the extent to which family members were willing to accept a diagnosis of AD.

Emergence of the Person with AD as Family Member

In the majority of studies of the family of a person with AD, the person with AD is typically absent (an exception in the studies discussed above is Le Navenec & Vonhof, 1996, who included participants with dementia if they wished to participate). This could be in part because many of these studies have focused on caregiving, thus positioning the person with AD as care-recipient, suggesting an implicitly passive role in the family. However, it could also reflect a bias prevalent in much of the dementia research to excluding the person with dementia, in part because of concerns about the accessibility of their perspective (Cotrell & Schultz, 1993). For example, Garwick et al. (1994), whose study focused not on caregiving but rather on perceptions of living with AD, did not report whether the person with AD was included in family interviews or not. Their failure to report on this at all may reflect an implicit bias prevalent at the time toward excluding the person with AD.

More recently, there has been considerable attention to the importance of including people with AD in research (Downs, 1997), resulting in a small but growing number of studies that include people with AD in exploring aspects of family life. Keady and Nolan (2003) explored the perspectives of both family carers and people with

dementia in the early stages of the disease, identifying different patterns of how they worked, either together or not, to accommodate to recognized changes. Forbat (2003) analyzed narrative accounts, obtained through interviews, of a woman with dementia and her daughter about their past relationship and their current care relationship. She interpreted their narratives as intersecting storylines in which the ways that each woman positioned herself and the other served to highlight how long-standing relational difficulties influenced interpretations of dementia and dementia care in the present. Forbat argued that discursive analyses of talk with people with dementia and their family carers can identify ways in which service providers can help individuals to construct more positive interactions with their kin. While the challenges of including people with AD in research have been acknowledged (Downs, 1997), analyses of their talk as equal participants in conversation offer a promising approach to accomplishing this goal.

Families, Alzheimer's Disease, and Conversation

In contrast to the foregoing studies, which relied primarily on interviews with one or several individuals for data, a small number of studies have focused on the conversations of people with AD and their families. In some cases, the objective is to understand how families accommodate to the breakdown of linguistic-communicative abilities; in others, it is to explore how family members position themselves and their partners with AD through their talk.

Accommodating to Linguistic-Communicative Breakdowns

Communication difficulties have long been recognized as a significant source of stress for families with AD (e.g., Orange, 1991; Savundraganayagam et al., 2005; Small,

Geldart, & Gutman, 2000). Findings of studies such as these have motivated several studies of conversations between individuals with AD and family members to identify sources of communication breakdown that could be mitigated by compensatory strategies.

Hendryx-Bedalov (1999), in a study of requests, found differences between the conversations of clinical dyads (each comprising a person with AD and his or her spouse) and those of matched non-clinical dyads in effectiveness of discourse in eliciting outcomes to requests. She also found that differences in communication styles among caregivers contributed to outcomes, linking those differences also to self-reported strain in the couples' relationships. In contrast, other studies have focused on more linguistic aspects of talk. Small and Perry (2005), taking into consideration the patterns of cognitive impairment in AD, explored conversational breakdowns in terms of the types of questions that spouses use with their partners with AD, including yes-no versus open-ended questions and contrasting those that draw on semantic memory (relatively spared) versus episodic memory (relatively more impaired). They found that breakdowns were most often associated with open-ended questions that placed demands on episodic memory; yes-no questions also were relatively more successful. A further finding was that, whereas frequencies of yes-no questions and open-ended questions were approximately equivalent, caregivers asked nearly twice as many episodic memory-related questions, most often about recent rather than remote past events, despite the relatively greater difficulty that these posed for their conversation partners. While the findings may have been influenced by the circumstances of data collection (asking dyads to record a conversation of approximately 10 minutes about topics of their choice), they

nonetheless raise intriguing questions about question use in everyday family conversations. As Small and Perry point out, differences in the pattern of question use in their study as compared with those identified in studies of conversations between unfamiliar partners and people with AD may be related to contextual influences of goals, shared history, etc. More intensive study of naturally occurring conversations between family members and individuals with AD is warranted to explore such differences further.

Use and effectiveness of widely recommended communication strategies have also been studied in brief recorded conversations between people with AD and family caregivers during different activities of daily living (Small, Gutman, Makela, & Hillhouse, 2003). While ten strategies were identified in the study, fewer breakdowns were associated with only a subset of these, including yes-no questions, eliminating distractions, and using simpler sentence structures; the latter strategy was used more frequently with partners with more severe dementia. One strategy, that is, slowed speech, was associated with more breakdowns.

These studies demonstrate clearly that our understanding of communication breakdowns can be informed by exploring the interactions of both the cognitive-linguistic impairments associated with neurological disease and the characteristics of the conversational patterns of interlocutors. However, in order to understand the implications of these interactions for families in their everyday lives, it is critical also to analyze conversations that are as natural and representative of everyday interaction as possible. To this end, repair strategies for the resolution of breakdown sequences between people at different stages of AD and their spousal caregivers have been

investigated in longer analyses of their dinner conversations together (Orange, Lubinski, & Higginbotham, 1996; Orange, Van Gennep, Miller, & Johnson, 1998). Although there was an increase of conversational breakdowns associated with disease onset and progression, and although responsibilities and strategies for repair (some more effective than others) shifted over the course of the disease, as in Hamilton's (1994) conversations with Elsie, these were nevertheless repaired successfully most of the time. Furthermore, the overwhelming majority of conversation was free of communication breakdown.

While these studies offer valuable guidance for the development of strategy-based intervention approaches to help families limit and resolve communication breakdowns, they also raise interesting questions. Orange et al. (1998) speculated that their findings of primarily trouble-free conversations, taken together with family caregivers' reports of high frustration and anxiety, might suggest that it is the type and not the absolute number of breakdowns that cause distress. Alternative suggestions are also possible, however. It may be that it is not changes in the nature of conversation breakdowns, but rather changes in the nature of conversation itself that leads to family distress. If we accept that roles and relationships are constructed through conversation, then changes in long familiar patterns of conversation may be free of breakdown and yet still be problematic for families. This aspect of family conversations has only recently attracted attention.

Roles, Relationships, and Alzheimer's Disease in Family Conversations

As discussed earlier, work such as Sabat and Harré's (1992) study has drawn attention to the role of interlocutors in positioning people with AD in social interaction. Clare and Shakespeare (2004) explored how family carers and their partners with early dementia positioned themselves in a five-minute recorded conversation together, the

purpose of which was to come up with a sentence describing their current situation (i.e., memory difficulties in the person with dementia). Their findings illustrated how couples used their talk to co-construct an account of their situation, identifying also dimensions of resistance as alternative positionings were constructed and contested.

In contrast to all the above conversations, which were between a person with AD and one family member (usually described as a family caregiver), there is one analysis of conversations among multiple family members including a person with AD. who was the author's mother-in-law (Brewer, 2005). Brewer's comment that "perhaps we can better understand the disconnect and discordance in their efforts to converse if we better understand the DAT individual before the disease interferes with family talk" (p. 88) emphasizes the special nature of family conversations which to date has been largely neglected. She associated features of her mother-in-law's talk, including her use of comments, questions, and topic shifts with constant changes in role, captured in Brewer's metaphor of carousel conversations. Her description offers a unique and valuable analysis of family conversation from the perspective of participants themselves.

Framing the Research Question

Clearly, conversations among people with Alzheimer's disease or related disorders and their families have much to offer in further our understanding of families' experience of disease, yet, to date, their full value remains relatively unexplored. In the present study, the broad research objective is to explore how understandings of diagnosed disease (i.e., AD and PPA) both shape and are shaped by conversations among persons with these diseases and their family members, taking into consideration both the

changing cognitive and communicative abilities of the diagnosed person and the meanings that different individuals give to those changes.

Several themes have emerged from the foregoing discussion that are useful in refining the research questions to be addressed in this study. First, differences in the way in which diagnostic categories are represented in public discourse suggest there may be advantages to including families with different diagnostic categories, one with a rich public discourse (Alzheimer's disease) and one without (progressive aphasia). Second, different ways of defining family suggest that, in a study that seeks to understand family perspectives, preference should be given to family decisions as to how it constitutes itself. A corollary to this is that, if the family is to be considered as a unit, all members of the family should be included, including the person with the diagnosis.

Given the foregoing, the broad research objective can be restated as four questions:

1. What changes in conversation and other aspects of family life do family members associate with a diagnosis of progressive cognitive decline?
2. What meanings do individuals give to those changes?
3. How are those meanings constructed in everyday conversation?
4. What are the implications of those individual meanings for the family as a unit?

The rationale for this project is that its results will further our understanding of the complex interaction between diagnostically determined cognitive decline (i.e., disease) and the family's experience of that decline (i.e., the illness experience). Given the central role of conversation in family life, such understanding is critical both to researchers and

to practitioners responding to families' requests for guidance in coping with these diseases.

CHAPTER THREE

METHODOLOGY

The goal of this qualitative study is to explore changes in family conversation associated with a diagnosis of dementia, the meanings associated with those changes for family members, and the implications of those meanings for the family as a unit. This focus on meaning necessitates a theoretical and methodological orientation that acknowledges the centrality of how people construct meaning in their everyday lives. The chapter begins with a discussion of such an orientation. Several principles of qualitative inquiry have informed the study, including considerations in using a case study design, triangulation of methodological approaches, and transparency of all procedures of data collection and analysis to ensure authenticity. In the last part of the chapter, I describe these principles and procedures.

An Interpretivist Orientation

If we accept that the meanings that families give to changes associated with disease are central to their concerns about those changes, then it is essential to approach questions about how they accommodate to such changes within a theoretical and methodological framework³ that gives centrality to how people construct meanings. Human beings are actors; we make sense of our world through our interactions with it in a process that, because we are also reflective, is ongoing and interpretive. Further, because the human world is a social world, an understanding of human experience necessitates attention to social interaction in group life. Prus (1996), arguing in favour of

³ In the context of this discussion, I am using "theory" in the sense that Prus (1996) described: "Social theory, or ideas about how group life takes,...." (p. 33).

an interpretivist approach, contended that these characteristics of human behaviour justified a different approach to its study than the positivist approach of the physical sciences:

Human life is studied as it is experienced and accomplished by the very people involved in its production. The interpretivists are centrally concerned with the meanings people attach to their situations and the ways in which they go about constructing their activities in conjunction with others (p.9)

To fail to take into account the interpretive, interactive processes of human behaviour, Prus argued, is to overlook the fundamental essence of that behaviour.

Several interpretivist approaches to the study of human experience have emerged over the past several decades including, for example, ethnomethodology (Harold Garfinkel), dramaturgical sociology (Erving Goffman), phenomenology (Alfred Schutz), social construction of reality (Peter Berger and Thomas Luckmann), and symbolic interactionism (Herbert Blumer). While there are commonalities among these approaches, there are differences that reflect not only the various disciplinary traditions within sociology and ethnography in which they were rooted but also the emphasis on particular aspects of social life that came under study. Over time, differences among approaches have blurred and shifted as they have continued to evolve, and contemporary interpretivists frequently combine elements of several approaches.

Symbolic Interactionism

The symbolic interactionism of Herbert Blumer is particularly relevant for the present study because of its emphasis on talk in interaction. Blumer's work was strongly influenced by George Herbert Mead, for whom language was a fundamental part of the human essence; "language – or the symbolic means of achieving a sharedness of

perspectives – was envisioned as the medium that made interaction possible” (Prus, 1996, p. 52). In linking symbolic interaction to meaning, Blumer (1969) posited three premises:

The first premise is that human beings act toward things on the basis of the meanings they have for them....The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (p. 2)

These premises direct our attention to the interwoven processes of interaction and interpretation that characterize social behaviour, described in Blumer's discussion of Mead's contributions:

A society is seen as people meeting the varieties of situations that are thrust on them by their conditions of life. These situations are met by working out joint actions in which participants have to align their acts to one another. Each participant does so by interpreting the acts of others and, in turn, by making indications to others as to how they should act. (Blumer, 1966, p. 541.)

Symbolic interactionism is particularly well-suited to a study of family; this becomes evident if we substitute “family” for the word “society” in the foregoing quote. LaRossa and Reitzes (1993) pointed out the value of symbolic interactionism in family studies, both because of its emphasis on family as a social group and because of “its assertion that individuals develop both a concept of self and their individual identities through social interaction, enabling them to independently assess and assign value to their family activities” (p. 136). Their comments again emphasize the importance of both interpretation and interaction, at the same time reminding us that it is through the interactive voices of individual members that we can learn about a family as a social group.

The human capacity for reflectivity and interpretation means that people can conceptualize aspects of their own experience as objects of thought; people can talk about meanings of those objects, but it is only through studying interaction that we can begin to understand the process by which meanings are created. Methodologically, Blumer's interpretivist approach became closely associated with an ethnographic research tradition (Prus, 1996). Ethnography offered the methodological tool of participant observation, in which the researcher, by becoming a participant in the group he is studying, seeks to become as familiar as possible with the perspectives and experiences of the other. However, other approaches too have contributed to the study of interaction, most notably in the areas of conversation analysis and interactional sociolinguistics, both of which focus on talk-in-interaction.

Conversation Analysis: Talk-in-interaction as Social Order

While research based on the theoretical and methodological principles of conversation analysis extends over a thirty-year period and continues to be widely influential in current approaches, the work of Sacks, Schegloff, and Jefferson is generally cited as foundational (e.g., Pomerantz & Fehr, 1997). Although their work illustrates the application of theoretical principles underlying conversation analysis (e.g., Sacks, Schegloff, & Jefferson, 1974), more explicit discussions of its origins and theoretical assumptions are found in the work of others. Heritage (1984) describes conversation analysis in the context of Garfinkel's work on ethnomethodology. Ethnomethodology is concerned with the everyday practices through which social order and social organization are constituted for and by its members. This focus on order differentiates it from symbolic interactionism with its primary emphasis on meaning; however, the two

approaches share a concern with the interpretive activity that interactants must undertake to accomplish joint action. While Garfinkel's work has influenced several approaches to the study of conversation, Heritage makes it clear that it is central to the development of conversation analysis.

A point repeatedly emphasized in descriptions of conversation analysis is its view of conversation as social action (Heritage, 1984; Pomerantz & Fehr, 1997; Sharrock & Anderson, 1987). Goodwin and Duranti (1992) suggest that Garfinkel's and Sacks' recognition of the central place of language in social organization is apparent in that they equate the basic social actor with mastery of natural language (p. 28). However, others (e.g., Heritage, 1984, p. 235; Pomerantz & Fehr, 1997, p. 65) cite Sacks' claim that his interest in conversation stemmed not from any interest in language nor from any theoretical priority of what should be studied but, rather, because tape-recorded conversations were readily available and could be repeatedly subjected to analysis. Irrespective of the difference in these accounts, the point to keep in mind is that conversation analysis studies how social interaction is organized in ways that are mutually interpretable to participants. The significance of the 1974 paper by Sacks, Schegloff, and Jefferson is that it exemplifies how highly systematic, structural properties of conversation can be found across different conversational contexts; these properties are a resource for participants in socially organizing their activities. It also established a rigorous methodology for the empirical study of conversation, emphasizing repeated listenings, careful transcription, and a refusal to establish a priori categories for analysis, arguing that all phenomena, no matter how apparently disorderly or random, are potentially relevant to emergent orderliness.

Interactional Sociolinguistics: A Focus on Meaning

Schiffrin (1994), in an overview of several approaches to the study of discourse, described the view of discourse within interactional sociolinguistics "as a social interaction in which the emergent construction and negotiation of meaning is facilitated by the use of language" (p. 134). Also key to this approach is the importance of context: meaning is always contextually situated, and the project of interactional sociolinguistics is to explore how situated meanings vary in different contextual frameworks. Schiffrin acknowledged the contributions to interactional sociolinguistics of Gumperz, a linguistic anthropologist whose analyses of interactions between members of different cultural groups highlighted ways in which "the meaning, structure, and use of language is socially and culturally relative" (Schiffrin, 1994, p. 98), reflecting macro-level social meanings but at the same time providing individuals with resources ("discourse strategies" in Gumperz's terms) to convey particular meanings.

A second significant contribution to interactional sociolinguistics, according to Schiffrin (1994), came from the work of Erving Goffman, which focuses on "situated knowledge, the self, and social context" (p. 102). Goffman's work, like symbolic interactionism, proposes a view of the self as socially and interactively constructed. In contrast to symbolic interactionism, however, Goffman's work emphasized face-to-face interaction, attending to how interactants position themselves and others through their talk. He pointed out that interactants must not only take into consideration the cognitive capacities of their interlocutors; they must also consider constraints imposed by politeness rules (Goffman, 1983). Interactional sociolinguistics, drawing on this work, identifies discourse strategies that allow speakers, through their talk, to achieve broad

interpersonal goals. Schiffrin is careful to differentiate such accomplishment from intentional motivation, claiming that attentiveness to context ensures that “what interactional sociolinguistics does is ground motivation in context – such that both the meaning and the motivation of an utterance are contextualized” (p. 132).

While interactional sociolinguistics shares many of the methodological tools of conversation analysis, the two approaches are strongly differentiated in their interpretation of context. For conversation analysts, context is relevant only as it is constituted through talk. The analysis of differences in situated meanings according to the context in which they are considered, so central to interactional sociolinguistics, is simply not possible in conversation analysis. Cicourel (1992) pointed out that “when the research analyst is working in her or his own society, and the reader is expected to be from the same society, it is especially convenient to use brief, formal or informal mundane conversations” (p. 294). However, he argued for the necessity of a more ethnographically-informed approach if the analyst was not a member of the same social group as the participants. In a study of family life through their conversations, the ethnographically-informed approach of interactional sociolinguistics with its emphasis on situated meanings is particularly appropriate.

Diagnosis, Family Life, and Conversation in Family Discourse: Two Approaches

A unifying theme underlying all methodological approaches of this study is that our social world is constituted through talk. Within this view, however, one can differentiate between the objects of talk and the process of talk. Symbolic interactionism, in emphasizing the reflectivity of the human actor, suggests that we are capable of

conceptualizing our experiences in ways that allow us to reflect on and talk about them. Possible methods for exploring meanings as objects of talk include open-ended interviews; however, as Prus (1996) cautioned, the researcher must constantly recheck his or her interpretations in a process of constant comparative analysis to ensure that participants' meanings are represented. In exploring meanings in a family, interviews with each member of the family provide a foundation for understanding family meanings, which are jointly constructed but socially distributed across individual members.

Symbolic interactionism also envisions interaction as the process of making meaning, although it is the approaches of conversation analysis and interactional sociolinguistics that provide the tools for analyzing talk as process. This emphasis on language in interaction allows us to explore how meanings are assigned in the everyday conversations of participants (Gubrium & Holstein, 1993).

These two different but related views of talk lead to two methodological approaches: in-depth interviews to explore key concepts as objects of talk, and analysis of naturally occurring family conversations to explore how those concepts are constituted in everyday talk itself. Triangulation of these two approaches, consistent with the overall framework of symbolic interactionism, ensures a more richly textured understanding of how family members construct meanings of disease in and through their talk.

The Case Study

A qualitative collective case study approach (Stake, 2000) is particularly well suited to the exploration of conversations in families with dementia in that the topic's multifaceted, comprehensive nature necessitates the integration of multiple

methodological approaches and analyses. However, as Stake points out, the selection of a case study approach is not itself a methodological choice, but rather a selection of what is to be studied. Ragin and Becker (1992), in a similar vein, state that any case study must address the question: what is this a case *of*? Ragin (1992) suggests that cases can be differentiated along two dimensions: the extent to which they represent either particular (i.e., specific) or general instances and the extent to which they are either empirically or theoretically constructed.

For this study, I propose to construct two cases as particular instances that incorporate previously established theoretical constructs of family and of diagnosed disease: in each, the family is considered as a unit of analysis, one including a member with Alzheimer's disease, the other including a member with nonfluent progressive aphasia. Both Ragin (1992) and Stake (2000) use the term *instrumental* to describe such cases. In an instrumental case study the researcher defines critical issues in advance and can thus take advantage of previously identified data collection and analysis methods (Stake, 2000). At the same time, the case itself, even if identified instrumentally, must be regarded as a particular case. It is essential to keep in mind that, even if the case is described as typical, one cannot generalize from it to other cases. What can be gained from the present study is not an understanding of how families negotiate and construct meanings but, rather, how particular families do so. Such understanding is not intended to provide answers so much as to provide clinicians and researchers with insight into new, more productive ways to formulate their questions.

A critical point in a collective case study lies in the way in which data are integrated across cases. It is essential that each case be analyzed separately. Stake (2000)

points out that comparative analysis can obscure knowledge that fails to facilitate comparison, leading the researcher to miss the case's own issues, contexts, and interpretations. Ragin (1992), in discussing comparative analysis in a case study approach, emphasizes the importance of comparing cases, not variables, suggesting that it is the comparison of variables that tends to obscure the case. While comparison is not intended to guide the analysis, the value of two cases is that, in addition to what each can contribute in its own right to our understanding of communication in families, each case may also suggest productive perspectives to consider in the other.

Procedures

Participants

Participant families were recruited through a multidisciplinary clinic specializing in the diagnosis of Alzheimer disease and related disorders. Clinicians identified potential participants using the following eligibility criteria:

1. The family included one person diagnosed either with probable or possible Alzheimer disease (AD) according to NINCDS-ADRDA criteria (McKahn et al, 1984) or with nonfluent progressive aphasia (PA), according to consensus criteria for the diagnosis of fronto-temporal dementias (Neary et al., 1998).
2. All participants were fluent English speakers, and English was their language of interaction in the home.
3. The diagnosed person lived in the community (i.e., not in a long-term care facility).

4. The diagnosed person had at least two local family members who maintained regular contact but did not necessarily live with that person⁴.

Letters of information were given to only two families, one with a member with AD and one with a member with PA. A member of each family expressed interest in the study and requested further information. Because both the recruitment process from that point and characteristics of the two families themselves shaped the findings, these are described in Chapter Four.

Ethical Considerations

The nature of this qualitative inquiry necessitated attention to several ethical issues at the outset and throughout the course of the study. First, the issue of informed consent was potentially problematic for two reasons, the first associated with seeking consent from a participant with cognitive impairment and the second associated with the exploratory nature of the study. With respect to seeking consent from participants with cognitive impairment, specifically memory loss, it was important both to re-inform participants and to re-seek consent at every point of data collection; this was done verbally throughout the study. With respect to the second concern, the exploratory nature of the study precluded an explanation at the outset about exactly what procedures would be involved and what the expected outcomes would be. This concern was mitigated by maintaining ongoing contact with participants, informing them of progress and results, requesting consent for proposed next steps, and inviting them to share any questions, comments, or concerns throughout the study. Letters of consent are included in Appendix A.

⁴ Although no a priori definition of "family" was given to the families, for the purposes of recruitment it referred to individuals who were identified in the assessment process as next of kin. Both families were invited to identify "family" and "regular contact" according to their own criteria (see Chapter Four).

A second area of concern centered on issues of confidentiality and anonymity. While the unit of analysis for the overall study was the family, it was individuals who were the informants and, within the family, anonymity of these individuals could obviously not be ensured. Participants were justifiably concerned that they might choose to disclose information to the researcher in order to ensure an accurate interpretation of their experiences, but they might also prefer that that information not be shared with other family members. This issue was problematic in that the exclusion of relevant information could potentially weaken the overall analysis but, clearly, these individual concerns were more important. Accordingly, participants were assured that they would have the opportunity to review all quotes, comments, and interpretations from their own interviews to be included in a final write-up before that write-up was shared with others.

If a description of a particular family achieves richness and authenticity, it precludes anonymity, at least from readers who know the family. Confidentiality can be preserved to some extent by the use of pseudonyms, the avoidance of specific geographic references, and the use of general rather than specific descriptions of personal information (e.g., type of employment) where possible. However, anonymity cannot be guaranteed. This issue was discussed with each family member, both at the outset and throughout the study, and each one acknowledged and accepted the possibility that his or her family could be recognizable to people who know them.

Data Collection

Interviews

Individual in-depth interviews were conducted with each family member, including the participants with AD and PA, at the beginning of the data collection period for that family, in a location selected by the participant. Interviews were conducted using an open-ended question format with an interview guide (see Appendix B), and covered three topic areas: the participant's understanding of the diagnosis, changes in family life associated with the diagnosis, and changes in conversation associated with the diagnosis. Interviews ranged from fifty to ninety minutes. All interviews were audio recorded and transcribed orthographically for subsequent analysis. If questions about specific content arose during analyses, participants were contacted by telephone for clarification.

Follow-up interviews were conducted with each family after the initial analysis and write-up of interview findings, approximately a year after the initial interviews. Prior to the second interview, participants were given a copy of excerpts from the write-up containing quotes (and contextualizing information) from their initial interview and asked to review it. The procedure differed for the two participants with AD and PA, in that I went over the written excerpts with them during the interview, rather than asking them to review the material beforehand on their own. The purpose of the follow-up interviews was twofold: first, to seek consent to include the excerpts and, second, to ensure that I had not misinterpreted the participant's comments.

Conversation Recording

After learning about the overall goals and design of the study, family members were invited to record conversations that included the person with the diagnosis, encouraging them to select conversations that they considered representative of their interactions together. A requirement of the study was that all parties involved in the conversation be informed and give consent prior to the recording, although an exception was made for young grandchildren: their participation was at the discretion of their parents. Participants selected the context for conversations, including setting, number of participants, and activities, as well as deciding whether to use digital audio or video recording equipment. Although video recording can capture more nonverbal and contextual information that may be relevant to the structure and content of conversation, it can also be more intrusive for participants and can limit settings in which data are obtained. For audio recording, family members were given a Sony MiniDisc player with an external bi-directional stereo microphone; this equipment was selected because it was easy to use, highly portable, and relatively unobtrusive. For video recording, a Sony digital video recorder with an external microphone was set up in participants' homes prior to the identified event with instructions on how to operate it. Conversational data are described in Chapter Four.

Participant Observation

As researcher, I participated in several visits over an approximately three-month period with each family, including different combinations of family members. One visit with members of each family included the recording of our conversation. During these visits, I used techniques of participant-observation (Emerson, Fretz, & Shaw, 1995),

documenting observations through fieldnotes recorded immediately after the visit.

Although these data from the participation observations were not formally analyzed, they served to enrich my understanding of each family, mitigating to some extent the loss of data resulting from the use of audio rather than video recording. A schedule of all interviews, participant observations, and recorded conversations for each family is given in Appendix C.

Journals and Diaries

Although at the outset of the study, provision was made for participants to record their observations, thoughts, questions, and/or concerns throughout the course of the study, initial discussion with participants suggested that this would not be productive. Accordingly, this was omitted from the study.

Data Analysis

A key principle of data analysis in this study is that, although it incorporates separate, methodologically distinct procedures, the results of each analytic procedure must be interpreted in the context of the others if an integrated account is to be achieved. Charmaz and Mitchell (2001), in a discussion of the benefits of combining the analytic methods of grounded theory with the data-rich approach of ethnography, illustrate how such combination necessitates a selective use of procedures that can be justified within the theoretical constraints of the research framework. Thus, description of the methods of analysis requires attention also to the methodological considerations and constraints that underlie them.

Transcription

The convention of transcription raises methodological issues. The representation of verbal into written format is problematic in that "transcription is a selective process reflecting theoretical goals and definitions" (Ochs, 1979, p. 44). The methodology of conversation analysis seeks to minimize this selective process, in that analysis is based on repeated listenings of recordings, not on a written transcript. The transcript is intended to represent those features that are empirically identified through those repeated listenings as relevant to analysis. However, even this methodologically rigorous approach is problematic. First, recordings themselves (particularly audio recordings) are obviously limited in the extent to which they can capture relevant features of actual conversations. Second, a strictly empirical approach to transcription, even if confined to the verbal signal only, risks resulting in a degree of detail that overwhelms both analysis and readability. Accordingly, many conversation analysts rely on previously developed transcription conventions that direct attention to particular features that have been shown to be relevant in previous analyses. These transcription conventions vary in how they represent speakers' utterances and interactions and in the amount of data (e.g., non-verbal, prosodic, contextual) that they include in transcription.

In the present study, transcription both of interviews and of family conversations was based on the transcription coding system developed by Gumperz and Berenz (1993), primarily because this system is based on a theoretical view of conversation as collaborative and so focuses on interactional features. However, in keeping with the empirical approach of conversation analysis, modifications to capture potentially relevant features were incorporated. A key to transcription notation is given in Appendix D.

The decision to use detailed transcription of interviews reflects a theoretical bias claiming that attention to how, in addition to what, words are spoken can enrich our understanding of their situated meaning. In reporting findings, however, for reasons of

readability I have omitted those aspects of notation that are not, in my view, germane to the point that I am making. I have retained pauses and placeholders (“um”, “uh”, etc.) because without these hesitations, speakers’ comments take on a certainty that is not evident in the original context. In some cases, I have omitted part of a quotation. These sections most often include backchannelling on my part (e.g., “mmhm,”); because the analysis ultimately did not focus on the interview as a collaborative construction, these did not contribute to interpretation. Occasionally, however, false starts and/or repetitions that did not contribute to the substance of the quote were omitted also. Again, the primary purpose of omitting these types of speaker self-corrections was to facilitate readability.

While the same system of transcription was used for both the interview and the conversational data, the process of transcription was different for each. Interviews were transcribed in their entirety prior to analysis in order to facilitate line-by-line coding as a first step in analysis. Conversations, in contrast, were analyzed, coded, and interpreted using a software program (ATLAS.ti 5.0) that allowed repeated listenings of selected quotations of digital audio recordings. Accordingly, for the conversational data, the primary goal of transcription was to provide a representation of this audio-based analysis for the reader, so that only those segments of conversation that were included in the final analysis and write-up were transcribed. Nevertheless, the process of transcription itself was an iterative one that led to re-examination and refinements of data interpretation.

Key Concepts as Objects of Talk: Analysis of Interviews

The goal of the interview analysis was to explore the intersection of three key concepts, that is, diagnosis and disease, changes in family life, and changes in

conversation, as part of the stock of knowledge of each individual member and, by attending to overlaps and differences, of the family as a whole. Although primarily descriptive, such an analysis also is interpretive in its attention to and selection of features that are accordingly constituted as relevant; it is this process of analysis that moves beyond description of the participants' accounts to an interpretation of the meanings that emerge from them, both for individual participants and for the family as a unit. Data from each family were analyzed separately; consideration of the two cases together was undertaken only at the level of final discussion.

A key principle guiding the analysis of interviews was the differentiation of *patterns* and *themes* (Luborsky, 1994), which facilitates the identification of researcher's versus participant's perspective. In Luborsky's view, patterns are findings that are identified and described in terms of the researcher's frame of reference; they are not necessarily relevant or evident to the participants themselves. Themes, in contrast, are findings that are marked by informants themselves as meaningful, described by Luborsky as "manifest generalized statements by informants about beliefs, attitudes, values, or sentiments" (p. 195). He suggests several ways in which themes can be identified including, for example, noting statements that are frequently repeated or assertions that are verbally highlighted as significant. This approach to analysis is one way of ensuring that readers can identify the perspectives represented in description, thereby increasing the authenticity of the report.

The first step in analyzing interview transcripts was line-by-line open coding; open codes, generated from the data itself, were single words or phrases that described the content of the segment (e.g., "mother's difficulty cooking", "feeling embarrassed").

Open codes were revised and refined throughout the process of coding all transcripts within a family. In the second step, which occurred throughout the process of coding, open codes were clustered together into higher-order selection codes as patterns and themes began to emerge within the three topic areas of diagnosis, family life, and conversation. For example, the open codes of “mother’s loss of cooking ability”, “mother’s cooking expertise”, and “mother’s cooking inspiring others” were grouped together within the theme of “mother’s role as family cook”. This was designated as a theme because it was signaled as important by participants themselves, appearing in several interviews and described at some length. The final step of analysis involved the careful examination of patterns and themes within topic areas to explore for overlaps and contradictions, both within and across members’ accounts, that could be integrated into a final description of the family unit as a whole.

Key Concepts as Process of Talk: Analysis of Conversations

In order to analyze conversational data, all recorded conversations were loaded into the software program ATLAS.ti 5.0 as audio files, each as a primary document. This included the video recorded conversation, for which the audio signal only was analyzed; the video recording served as a reference for clarification of context and, occasionally, to help sort out participants’ voices in overlapped conversation. Primary documents were then segmented into quotations that could be subsequently coded. Segmentation was generally accomplished on the basis of conversational topic structure, with topic being defined heuristically as “what people are talking about” rather than theoretically. The concept of topic, while intuitively familiar, is complex both theoretically and analytically (Brown & Yule, 1983); however, as the primary purpose of segmentation was to break

apart the data into manageable chunks, this was not an issue. In some cases, segments within segments were identified as quotations to capture specific features of interest in the data.

The first phase of analysis was to identify segments that could be excluded from further analysis, either because they were inaudible or because they were not part of the conversation according to the criteria established at the outset, for example, if the person with AD or PA left the room or was alone in the room with a grandchild. Extended periods of silence were identified also at this point; while silence is part of the interaction and was acknowledged as such, in an audio recording it is itself not analyzable. This sorting process was accomplished by assigning "decision codes" to each segment, including "omit" with a reason also coded (e.g., omit, silence), "transcribe", or "transcribe?." The latter code was used to signal segments that included discussion of personal information that could be sensitive in a public forum, for example, the illness of an extended family member. These segments were all included in analysis but were not selected as examples if the point of relevance could be made using less sensitive quotations.

In the second phase of analysis, open coding was used primarily to describe topical content ("topic codes", e.g., "Maria's bike trip"), but also as an initial step in capturing interactional features that seemed particularly significant ("conversational feature codes", e.g., "Rose's [person with AD] topic introduction"). Contextualizing information was coded also ("environment codes", e.g., "child care activity"). Typically, multiple codes were assigned to each quotation. As I moved through the primary documents of conversations within the family, open codes were in some cases revised

and refined (e.g., "Slocan Lake", "Rosebery", "Kootenays" were collapsed into a single code), but the purpose of this level of coding was a low level description to facilitate identification and retrieval of segments of the conversation.

The third phase of analysis integrated the interview and conversational data. Codes were developed on the basis of interview findings, prefixed either by "fc", indicating consistency with comments from one or more family members, or "ob", indicating that my observations were relevant to the family interviews, but either as contradiction or as something not commented on by them. An example of an "fc" code is "fc safe topic", reflecting a daughter's comment that her mother with AD tended to talk about particular topics that the daughter interpreted to be safe; an example of an "ob" code is "ob testing", reflecting a husband's use of questions to test his wife's recall of specific information.

In the fourth phase of analysis, "fc" and "ob" codes were clustered into larger groups that captured emerging patterns; these were assigned higher order codes. Examples of higher order codes are "fc family strategies" or "ob role conflicts". Repeated listening to all quotations within each of these groups led to further refinement of coding. As a final stage in analysis, moving to write-up, quotations exemplifying key points were selected for transcription. As noted above, the process of transcription itself, with the repeated listening at a micro level that it entails, led to yet further refinement. In the final writing of selected quotations, analysis drew on the work of conversation analysis (CA) (e.g., Sacks, Schegloff, and Jefferson, 1974) to capture structural features of conversation that informed interpretation, as well as interactional sociolinguistics with its emphasis on interaction features (e.g., Schiffrin, 1987).

Throughout the process of analysis, comments were written for quotations identifying particular features of interest such as, for example, which specific features of the talk within a quotation led to the assignment of a particular code. In addition, memos were written to document the development and refinement of codes during the iterative process of analysis. Memos were used also to keep track of theoretical or methodological issues arising in the process of analysis.

As noted earlier, each case has been analyzed in its entirety using the above procedures, so the iterative process of analysis was used only within and not across cases. Results of these analyses are presented in Chapters Five and Six, following an introduction to the data in the Chapter Four.

CHAPTER FOUR

EMERGENT FINDINGS

Introduction

The following pages provide an introduction to the findings by describing the ways in which the study evolved as participants were recruited, interview and conversational data were collected, and analyses were undertaken. It begins with a description of the participants themselves (identified by pseudonyms) and of the conversations that they chose to record, followed by a discussion of methodological issues that arose in the course of the study with respect to interviewing participants with cognitive impairments.

Study Participants

Two families agreed to participate in the study. In each family, though not by design, the person diagnosed with the disease (either primary progressive aphasia or Alzheimer's disease) was a married woman with adult children. In each instance, it was the husband who contacted me in response to a brochure about the study, given to the couple by a clinician at the clinic where they received the diagnosis. In each case, I met first with the husband and wife to give them more information about the study and to ask them about other family members (without defining "family") who might be interested in participating. Although it was possible that in-laws or siblings could have been included, this was not the case; in both instances, the couples identified their adult children only, and neither of the two married adult children suggested including their spouses.

The Tanaka family includes Rose, a seventy-four year old woman who was diagnosed with Alzheimer's disease some months prior to the study, her husband Tom

(also in his mid-seventies), and their three adult children, Linda, Maria, and Colin. The family is Japanese-Canadian, with both Rose and Tom having been born in Canada. Both Rose and Tom had lived all their lives in the city in which this study was conducted, with the exception of a period of internment during the Second World War, an event to which they referred in our earliest conversation and which came up on several occasions after that.

The Tanaka adult children were all between the ages of thirty and forty, with Linda the eldest and Colin the youngest. All three lived in their own homes with their partners; only Colin had children, aged six years and one and a half years. All three of the Tanaka adult children had university education, as did Tom. All members of the Tanaka family were (in the case of the children), or had previously been (in the case of the parents), employed in their own businesses.

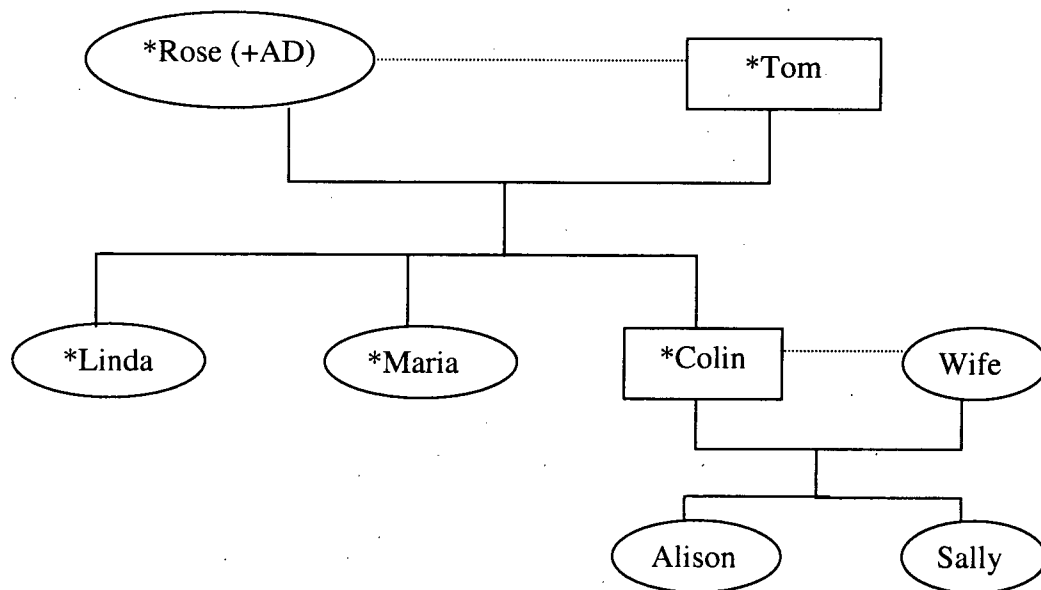


Figure 4.1 Tanaka family members. Asterisks mark participants who were interviewed. All named participants took part in at least one conversation.

Rose's first language is Japanese; she learned English as a young child and has spoken both languages throughout her life, speaking Japanese with friends or older family with little or no English. Rose's English is influenced by Japanese in both accent and grammatical usage. Although Tom also speaks both languages, the language of the Tanaka home is English; the children speak little, if any, Japanese. To foreshadow the findings, Rose used only two Japanese words in over six hours of recorded talk, both in conversations with Tom. Thus, there was no evidence of the inappropriate code-switching that has been reported in the literature to be associated with AD (de Santi, Obler, Sabro-Abramson, & Goldberger, 1990).

The Thompson family includes Margaret, a sixty-three year old woman diagnosed with primary progressive aphasia several months earlier, John, also in his early sixties and now retired, and their four children, Angela, Christine, Stephen, and David, all in their thirties. Of the four, Angela is the only one who is married; she has two children,

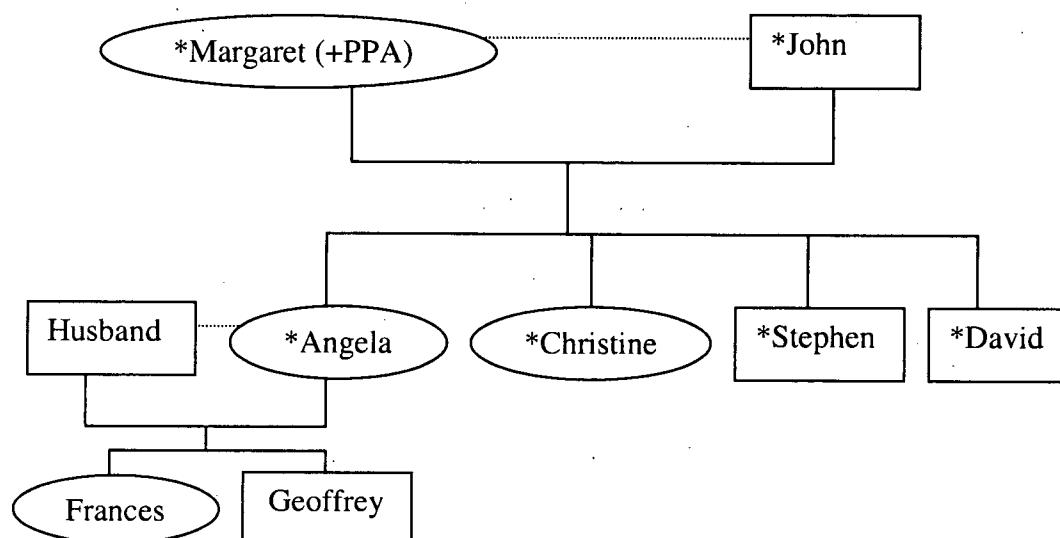


Figure 4.2 Thompson family members. Asterisks mark participants who were interviewed. All named participants took part in at least one conversation.

Frances, aged nine, and Geoffrey, aged three. She and Christine live in another part of the country, having moved to the city where their maternal grandmother still lives and from where their parents had originally come. Both daughters maintain regular contact by telephone and email, with visits from and/or to their parents at least annually. Stephen lives in the same city as his parents, maintaining contact by visits and telephone; at the beginning of the study, David was living in a separate suite in their home. All members of the family except David hold university degrees, and the four children have all taken very different career paths.

Recruitment Process as a Reflection of Family Style

Despite similarities in the way in which families were initially contacted, the recruitment process from that point on was very different, and to some extent reflects differences in family styles of interaction. In the Tanaka family, after our initial meeting Tom contacted all three of their children and arranged a meeting so that we could all discuss the project together. When I met with the five of them, they discussed the project and agreed, as a family, to participate.

In the Thompson family, the process took place over a period of time, with recruitment of different family members at different times. This was in part because of the family's particular circumstances: Angela and Christine lived in a different city and it was not clear initially when they would be next visiting their parents. However, it also reflected a different interpretation of participation, with more emphasis in the Thompson family on the choice to participate being up to each individual, rather than as a family decision. John suggested that as a first step he would discuss the project with his

youngest son, David, who at the time had the most frequent contact with his parents. At David's request, I met with him separately, and he expressed cautious willingness to participate. Accordingly, I arranged my first interviews and conversational data collection with John and Margaret, with an interview with David to follow.

On a subsequent visit with Margaret and John, their eldest son, Stephen was staying with them for a few days and Margaret invited me to meet with him. I explained the project to Stephen who, although he lived within driving distance of his parents, saw them much less often than did his younger brother. He too expressed interest in the project and, accordingly, met with me for an interview in addition to participating in conversational data collection.

An opportunity to meet with remaining family members arose when Margaret and John's two daughters came home for a family visit. John and David both suggested the possibility of my meeting with the daughters during their ten-day stay, and both daughters willingly agreed. It is important to note here that their interviews were necessarily scheduled on the first full day of their visit, so that at that point they had had little time to talk with other members of the family in person.

Ultimately, it took several months to interview all members of the Thompson family. Interviews with the Tanaka family were completed within two months, although collection of conversational data extended over a longer period.

Conversational Data

The choices made by participants in each family for recording conversations with Rose or Margaret provided some insight into the nature of their interactions together.

Almost all of these conversations were recorded at mealtimes, underlining the importance of meals together as an opportunity for social conversation and family interaction.

However, there were some particular circumstances in recording for each family that warrant discussion.

Tanaka Family Conversations

The Tanaka family recorded, in all, eight conversations over a period of four months, one of which was video recorded, with the remainder audio recorded only. A descriptive summary of these conversations is given in Table 4.1:

Table 4.1

Tanaka Family Conversations

<u>Code</u>	<u>Participants</u>	<u>Setting</u>	<u>Length</u>
RLM	Rose, Linda, Maria	Lunch in local restaurant	39:28
RM1	Rose, Maria	Tanaka kitchen	14:47
RM2	Rose, Maria	Tanaka kitchen (same day)	51:22
RT	Rose, Tom	Tanaka kitchen, dinnertime	35:59
RTB	Rose, Tom, Barbara	Tanaka kitchen, morning coffee	60:16
RC1	Rose, Colin	Colin's home	19:42
RC2	Rose, Colin	Colin's home (same day)	Omit*
RTLTM	Rose, Tom, Linda, Maria	Tanaka kitchen, dinnertime (video)	74:32

* Conversation was excluded from analysis because it included an adult from whom consent had not been obtained prior to recording.

The activities in which participants were engaged during recordings were, in all cases, representative of the ways in which they spent time together (i.e., as described in their interviews). The conversations between Maria and her mother took place on the same day, when Maria came over to keep Rose company while Tom was gone for the day; during the interval between conversations Maria washed her mother's hair for her and helped her to sort through her clothes. The recording between Rose and Colin also took place while Tom was away for the day. During that recording, both adults were engaged with Colin's two young children, affording little opportunity for conversation together. The latter part of the recording has been excluded from analysis because it included only Rose and her granddaughter Alison, as Colin had left the room to put his youngest child to bed.

With the exception of the conversation between Colin and Rose, participants talked about the recording itself, most often at the beginning and end of the recording but, on occasion, at points throughout. Such comments draw attention to the potential influence of recording on family conversations, serving as a reminder that they may differ from naturally occurring, private conversations in ways that the participants themselves may or may not recognize.

Thompson Family Conversations

The Thompson family recorded a total of five conversations over a period of five months; one of these was briefly interrupted and so appears in two parts. Similar to the recording contexts used by the Tanaka family, one conversation was video recorded,

while the remaining four were audio recorded. A descriptive summary of these conversations is given in Table 4.2.

Table 4.2

Thompson Family Conversations

<u>Code</u>	<u>Participants</u>	<u>Setting</u>	<u>Length</u>
MJS	Margaret, John, Stephen	Dinner: Thompson kitchen	33:48
MJACD	Margaret, John, Angela Christine, David, Frances, Geoffrey	Dinner: Island cottage	33:13
MJAC	Margaret, John, Angela, Christine, Frances, Geoffrey	Dinner: Island cottage	37:51
MJAC2	Margaret, John, Angela, Christine, Frances, Geoffrey (video)	Dinner: Thompson dining room	38:37
MJB	Margaret, John, Barbara	Lunch: Thompson kitchen	64:35

As noted earlier, the selection of meals in all cases for recording conversations reflects the importance of mealtimes as an opportunity for family to come together. It is of interest with regard to the choice of recording settings for the Thompsons that no conversation was recorded between Margaret and just one other participant; to foreshadow findings from the interview data, this probably reflects the challenges for both Margaret and a single conversation partner in sustaining conversation. Margaret was willing to make a considerable effort to take part in the study; when I explained during our interview about collecting conversation recordings, she commented: "I will tr- try to uh..talk for you" (IM: 983). When I asked her on another occasion about the possibility of recording a conversation between just her and John, who was clearly her most frequent

conversation partner, her reluctance was so apparent that I emphasized that it was her choice entirely, and to say no if she preferred not to do that. Her "no" was clear and without hesitation; my interpretation of it as a reflection of the difficulty in sustaining two-party conversation will be explored further in the context of findings from interview and conversation data.

In contrast to the Tanaka family, several of the mealtime conversations that were recorded by the Thompsons represented, not routine events, but rather special events in their family. Conversations including Angela, Christine, and the grandchildren were recorded during a visit to their parents that marked the first time in several years that all the family had been together.

Similar to comments in the Tanaka family, participants' occasional comments either about the recorder or, in some instances, addressed to me as the absent listener, served as a reminder of potential influences of the process of recording otherwise private conversations.

A Clinician's Perspective

An important aspect of qualitative research is its acknowledgement of subjectivity and its insistence on the identification of different perspectives, including that of the researcher (Gubrium & Holstein, 1997). My perspective as researcher is grounded in my experience as a clinician, working as a speech-language pathologist with people with degenerative cognitive disorders. That clinical perspective is an important voice throughout the analysis because, for me, Alzheimer's disease and progressive aphasia were always present, forming as they did the context for my meeting these two families.

With respect to my clinical perspective, there is an important point to be made here with respect to use of language and its connotations. As discussed in Chapter Two, whereas *Alzheimer's disease* (or, more recently, *Alzheimer disease*) refers to the disease as a diagnostic entity, it is more often constructed in the public domain as *Alzheimer's*, so that these different terms can be associated with different contexts and subtle differences in connotative meanings. Rather than differentiating among these terms by creating specific definitions, and in order to avoid privileging any one usage, I have used the terms that best reflect those used in data sources (i.e, literature, participants' comments, etc.). Accordingly, all three terms, as well as the abbreviation "AD" are used throughout the following chapters. With respect to terminology for primary progressive aphasia, there has been a gradual shift, associated with the evolution of the diagnostic category itself, to "nonfluent progressive aphasia", sometimes shortened to "progressive aphasia". The terms primary progressive aphasia and progressive aphasia are most often used in the following chapters as well as, occasionally, the abbreviation "PPA". For these terms too an effort has been made to respect the terminology used in data sources.

Clinical Descriptions

Rose Tanaka and Alzheimer's Disease

Rose Tanaka was seen in 2002-03, over a period of several months, for a multidisciplinary assessment in a clinic specializing in the diagnosis of Alzheimer's disease and related disorders. On the basis of that assessment, the team made a diagnosis of probable Alzheimer's disease, while noting that ischemic changes were possibly contributing to her overall presentation. Specifically, the diagnosis took into

consideration Rose's history of syncope, with evidence of partial occlusion of the right carotid artery. In terms of cognitive status, Rose's score on the Modified Mini-Mental Status Exam (3MS; Teng & Chui, 1987)) was 22/30. Four months prior to data collection (Jan., 2003), she was placed at Stage 4 on the Global Deterioration Scale (GDS; Reisberg et al., 1982) described as "late confusional stage" (p. 1137). By March, 2004, four months after data collection ended, her GDS score was 6, described as "middle phase of dementia" (Reisberg et al., 1982, p. 1137). Together these scores indicate that during the time of the study, Rose had a mild-moderate cognitive impairment consistent with early Alzheimer's disease. Neuropsychological assessment revealed evidence of generalized cognitive decline across most domains, with the most marked deficits apparent in memory: moderate impairment was demonstrated in all aspects of memory functioning. Verbal skills showed greater impairment than did nonverbal skills, with visuospatial⁵ reasoning skills remaining relatively strong. The family was advised of the diagnosis in March, 2003, and Aricept was prescribed.

Margaret Thompson and Nonfluent Progressive Aphasia

Margaret Thompson was initially seen in the same clinic in February, 2002. At that time, she presented with word-finding problems that were noticeable to herself and others around her. Neuropsychological testing indicated borderline to mild impairment in psychomotor speed, mild impairment in mental flexibility, and language impairments. Visual perceptual abilities were good, and there was relatively good preservation of memory. Her score on the 3MS at that time was 29/30; her score on the GDS was 4. On

⁵ Visuospatial tasks rely on visual and spatial abilities, rather than on language. An example is a test of block design, in which the patient is required to reproduce pictured coloured designs using three dimensional coloured blocks.

the basis of all assessment findings, she was diagnosed with nonfluent progressive aphasia, with a differential diagnosis for fronto-temporal dementia. Later that spring, language abilities were further assessed by a speech-language pathologist who noted good preservation of semantic knowledge but impairment of word-retrieval and grammatical abilities. Comprehension at that time for written and verbal information was good. By August, 2003, (three months after data were collected for this study) when Margaret was seen for review assessment, her 3MS score had declined to 21/30, GDS score remained at 4. There were further deficits in verbal fluency and mental flexibility; in addition, she was beginning to show mild impairment in visuospatial problem solving, and there was moderate impairment of visual scanning abilities.

Challenges in Interviewing Participants with AD and PPA

Rose: Challenges in Maintaining a Common Frame

In the interview with Rose, a major challenge for me centered on maintaining the interview *as* an interview, while for Rose it frequently shifted from interview to conversation. Throughout, there were some characteristics of an interview: for example, consistent with my role as interviewer, my turns were much shorter, comprising questions for the most part (Lesser & Milroy, 1993). Rose's participation was consistent with that of interviewee in that she did not ask questions but acknowledged my right to ask them, with her responses always initially topically related to the question. In terms of topic management, in contrast, our interaction took on more of the characteristics of conversation, with Rose dominating the conversational floor. Generally, in interviews, both parties acknowledge the role of the interviewer in establishing the topic, in contrast

to conversations, in which topics are more collaboratively constructed. In our interaction, Rose's responses, though initially related to my questions, often moved to different topics stepwise through several topic transitions without yielding the conversational floor, sometimes returning to and repeating earlier topics that she had introduced. Sacks (1992) described such moves as *stepwise*, describing them as follows: "Such a move involves connecting what we've just been talking about to what we're now talking about, though they are different" (p. 566). He went on to associate such topic transitions with good conversation, characterized as one "in which, so far as anybody knows we've never had to start a new topic, though we're far from wherever we began and haven't talked on just a single topic, it flowed" (p. 566). The point is that such moves can and do occur in everyday conversation; because they are not characteristic of interviews, their presence frames that stretch of talk as conversation rather than interviews. While this move from interview to conversation happened occasionally in other interviews with members of both families, in those instances such moves were frequently introduced and always acknowledged as digressions, with an explicit return to the interview frame. In my efforts to regain control of the interview, I tended to alternate between the role of interviewer and that of conversation partner. As interviewer, I sometimes treated Rose's topic shifts as digressions, as I had done in other interviews, by explicitly re-establishing the topic, as in this exchange:

Excerpt 4.1

237. B:um:...{[h] can I just go back to talking about/}

238. R: =={[h] sure/}

239. B:the Alzheimer's for =a minute? is that okay/ =

distant and more recent events were conflated, making it difficult to draw inferences about changes that might be associated with Alzheimer's. For instance, she talked about how she preferred not to drive in rush hour to visit friends across town, while in fact she had not had a driver's license for at least five years. Similarly, when she described her activities with her family, it was not always possible to establish when these took place. Her descriptions nevertheless offer considerable insight into how Rose situated herself within her family.

Margaret: Challenges in Elaborating Meaning

In contrast to Rose, Margaret appeared to be very aware throughout the interview of the central theme of her disease, in this case, primary progressive aphasia. In addition, she had no apparent difficulty in accepting the interview frame. Nonetheless, there were challenges in this interview that were not encountered in any other. In particular, the underlying methodological assumptions of the semi-structured interview are not easily realized in interviewing a person with nonfluent aphasia of any etiology. The strategy of asking open-ended questions and then providing minimal feedback or interpretation during the interview is not at all compatible with the kind of conversational support needed by individuals whose communicative abilities are significantly compromised by progressive aphasia. For example, in response to my general question about how primary progressive aphasia has affected having conversations with people, Margaret's response was "I am finding them ..um/...quite difficult/" (IM.555) Further elaboration required further more explicit questions, with the obvious possibility of the interviewer's preconceptions intruding in unwanted ways. Other challenges are exemplified in the following exchange.

Excerpt 4.2

160. B: do you mean *that's how many people *go::,
 161. ==from having *primary pro*gressive aphasia to having *Alzheimer's?
 162. M: =*Alzheimer's// =
 163. B: =is that what you= mean?
 164. so it happens *sometimes?
 165. M: {[p] yes}//
 166. <3> [audible intake]
 167. <2> I'm..I um/...I- I-
 168. <10> I'm- I'm {[p/nw] reget}- re..*gretting having Al-..Alzheimer's//
 169. [hhh]
 170. it's - it's..it's a dementia of.. my *brain/
 171. and I uh..um/
 172. <10> I'm - I- I'm c- *cooking/
 173. and - and um..*baking..at um..my *best,
 174. B: mm*hm,
 175. M: and um/ .I - I have um/
 177. <8> I- I'm *grinding.. *wheat.. for the *bread,
 178. B: mm*hm, mm*hm,
 179. M: and um..I - I'm having..um_ <8> [hhhh]
 181. <4>
 182. B: you mean you're still *doing/
 183. you're =*doing= all those things//
 183. M: = yes = ==yes/

(IM.160-183)

In line 168, Margaret described “regretting” having Alzheimer’s, a comment that suggests she believed she actually did have it. The juxtaposition of the content of lines 173 to 179 and the lack of any intervening pause or topic closure indicators suggest that they are relevant to line 168, but Margaret did not make that relevance explicit. This led me to make two assumptions: first, that in lines 173 – 179, Margaret was describing activities that she could not have done if she had had Alzheimer’s and, second, that “regretting” was a verbal paraphasic error, that is, the unintended substitution of one word for another. In this case, the error “regret” was produced instead of the intended word “dreaded” and was further complicated by a phonemic paraphasia (i.e., sound

omission, shown in line 168). These assumptions in turn resulted in the following sequence:

Excerpt 4.3

189. B: == am I -
 190. ..um..{[h]I just want to get one thing}_
 191. ==I'm not quite clear/
 192. ==you *said you're -.. you're re*gretting having *Alzheimer's,
 193. do you mean =you're - you're a*fraid,=
 194. M: =*no I'm uh *no =
 195. B: you're =*dreading=
 196. M: =no =
 197. == I - I - I - I'm I'm **dreading *having *Alzheimer's//
 198. B: right/ okay//
 199. ==so..so you *don't have **that diagnosis//
 200. M: ==no//
 201. B: ==right//

(IM.189-201)

Even though Margaret's comment in line 197 appears to support this interpretation, it is possible that she accepted it as an easier alternative than further clarification, a kind of "close enough" interpretation. Consequently, in analyzing and interpreting Margaret's interview, it was critical to compare comments throughout the text, searching for both confirmatory and contradictory evidence before drawing any conclusions, as well as being particularly attentive to the possibility of leading questions and comments on my part.

CHAPTER FIVE

THE TANAKA FAMILY AND ALZHEIMER'S

Three topic areas were explored through interviews with the Tanaka family; they were also used to guide the analysis of family conversations. These topics included participants' understandings of Alzheimer's disease as a diagnostic entity, changes in family life associated with that diagnosis, and changes in conversational interactions associated with the diagnosis. In this chapter, findings within each of these three topic areas will be presented in two ways, first describing participants' understandings as represented in interviews and, second, describing how patterns and themes emerging from the interview data were constructed in family conversations. The chapter closes with a summary of key findings that address the research questions and a commentary on these findings.

Alzheimer's Disease: Diagnosis and Expectations

Interview Representations

From the Tanaka family's descriptions of the process of Rose's diagnosis of AD, there emerged several ways in which the diagnosis itself was incorporated into family understandings. Individual perspectives as well as subsequent understandings and interpretations inevitably influence retrospective accounts of the events leading up to diagnosis, so one would not expect complete congruence among family members. For the Tanaka family, there was a remarkable consistency in the three adult children's

descriptions of incidents and concerns; these, however, did not entirely accord with Tom's account.

All three adult Tanaka children had individually become concerned two to three years prior to the diagnosis about Rose repeating herself, forgetting significant events, and having difficulty in everyday activities: opening car doors, paying bills, adding up numbers. At first, they attributed these to normal processes of aging and to her doing too much. At the same time, Rose was undergoing tests to determine the cause of fainting spells that she had had for several years so, as they noticed more changes in her, the children considered that too as a possible explanation. However, as they continued to see her having problems, they collectively began to question the possibility of Alzheimer's disease, leading to Internet searches and sharing information with each other about what they learned. They also began to push their father to take Rose for medical assessment, an undertaking which, according to all three, he initially resisted.

In contrast to the children's gradual, growing awareness and concern about their mother's difficulties, Tom described a very sudden alerting to his wife's problems. The "key ..the thing that really got [him] going" [IT: 71], was when he learned that she had failed to pay their income tax. This led him to check her handling of other household activities and to ask Linda about her mother's activities in the office. Yet even at that point, in Tom's account there is a suggestion of resistance to the interpretation of something seriously wrong:

yeah/..and I think -...probably Linda/ ..
because Rose was spending a lot of time with Linda/
{[ppp] yeah/} uh...and I both recognized ..things were not right/
you know/ but uh/..you know/ we do ..tend to forget things/
it's a natural..{[p] thing/ you know/}
but uh..uh..so it's not as though/

..everything's fine on a certain day, and.. the next day/
you can't really pinpoint what ..*when roughly/ [IT: 240-250]

The attribution of changes in Rose's behaviour to normal processes, initially common to everyone in the family, may have persisted longer in Tom, an interpretation suggested by his own remarks:

the kids have been very supportive/ they have been very very.. caring/
..uh..in fact maybe – I hate to say this/
but maybe even more so than I –
I have- tend to be a little bit ..well,..laid back a bit/ [IT: 220-223]

Rose too acknowledged the support of her daughters in deciding to do something about her memory difficulties. When asked about events leading up to diagnosis, she described her daughters as being very good to her, recounting that they told her: "you're kind of .. a bit..losing your..uh .memory or something/" [IR: 275]. Rose's response to this appeared to be relief at having her subjective impressions supported, recollecting that she told them: "I'm glad you noticed that/ because I noticed this..this myself/" [IR: 277].

These combined concerns led to a series of investigations for Alzheimer's disease, taking place over about a one-year period, and resulting in that diagnosis.

Representation of Alzheimer's

Generally, the Tanaka family represented Alzheimer's as a disease of the brain, with little question as to what might cause it beyond some speculation, on Tom's part, about a possible genetic factor. He raised this question while acknowledging that, to the family's knowledge, there was no one on Rose's side suffering from AD; his speculation seemed to arise more from his awareness of research studies into possible genetic links, and his self-description as "a great believer in genetics" [IT: 611].

Individual family members' descriptions reflected how their own understandings of the disease shifted as they sought to learn more about it. For example, Colin explained how, before seeking out information, he had thought Alzheimer's was "just a..an old person's disease" [IC: 60], thinking it to be "sort of lumped in with that/ well/ they're just going senile type of thing/" [IC: 61] These views are reflected in Rose's remarks about having Alzheimer's disease; she commented: "it could be worse//" [IR: 56], going on to describe some of her older friends: "some of them..have really gone down// you know I'm not trying to put them down/ you can't help it/ it's a- that it's a disease or sickness/" [IR: 63-67]. In checking with other family members, I learned that no one else in the family was aware of any friends having Alzheimer's. This suggests that although Rose described Alzheimer's as a disease, it was, for her, more closely associated with aging. This interpretation is further supported by the finding that in her interview, specific discussion about Alzheimer's was consistently linked with Rose's shifting the topic to her age.

The understanding of AD as a disease characterized primarily in terms of memory loss was evident throughout the interviews. For example, Maria, describing Rose's gradual withdrawal from playing with her grandchildren, explained: "she wouldn't remember how to play tooth fairy/..so she would just sit there/ and kind of..watch/" [IM: 561-563]. However, there also was evidence that family members were aware that more than memory could be involved, as in Colin's comment describing what he had learned about the disorder: "I thought maybe it just affected memories, or how they remembered..certain things/ but uh..I didn't realize it affected her..I guess you'd call..cognitive ability?" [IC: 71-73]. Linda too, in talking about Rose's forgetting things,

commented: "I guess you're not suppo- they don't forget/ they just never really – never sunk in/ what they were 'sposed to do/" [IL: 331-332]. The use of the pronoun "they" in both Colin's and Linda's remarks suggests that this information came from what they learned about AD in general, rather than from specific observations of their mother. Tom, in contrast, questioned the involvement of abilities other than memory on the basis of his own observations of Rose: "I keep wondering/ gee/ is it-..because of memory loss, or is it because..some part of her brain/..has gone downhill so much/ that – even her..ability to..reason/" [IT: 692-694].

In addition to descriptions of AD in terms of cognitive functions, there were also references to more pervasive changes in Rose's ways of being. For instance, a theme of "childlike" emerged, although this description was in all cases somewhat tentative, with evidence of mitigation in each comment. Linda, for instance, talking about changes in her mother that she associated with Alzheimer's, described Rose as follows: "'cause actually now? I think she's...kind of child like in her- her um...demeanour?" [IL: 139], clarifying further: "she's actually got this kind of childlike...happiness? around her?" [IL: 145]. Linda's hesitation and rising intonation suggest a request for agreement, or support, from her listener in proffering the analogy. Yet it is an analogy that Rose herself used, describing being with her family and laughingly claiming: "oh/ we're like kids/" [IR: 713]. Tom, describing traveling with Rose said: "it's like..taking a ..a five year old kid with me/" [IT: 913], but then qualified: "well it's not as bad as that//..but it's just that I can't relax/" [IT: 915]. Maria, explaining how her mother told more stories now about the past, commented.."it's almost like the-...she goes back to childhood/" [IM: 709]. However, she too qualified the implications of her comment,

linking the behaviour to normal aging: “and I don’t know if that’s what you do anyways/ when you get older, but...it’s definitely a big part of it//” [IM: 711-712].

Another consistent representation of AD in the Tanaka family was that it spares physical abilities. Rose, in talking about the circumstances leading up to her diagnosis, described the absence of physical symptoms: “well physically, physically/ there’s nothing- and I didn’t have headaches, um..I had appetite” [IR: 245-247]. Her comments suggest an association of disease with physical complaints, an association that may partly account for her occasional insistence that she is “fine”. For others in the family, Alzheimer’s was described in terms of a dichotomy, as in Maria’s comment that “her body may hold up, but her brain is gonna..eventually..uh..go,” [IM: 11]. The implied acknowledgement of a mind/body dichotomy may also account for Colin’s apparently contradictory remark: “I see my..my mother/ as sort of fully functional otherwise, but starting to lose..um..her capabilities/” [IC: 67-69].

Diagnosis as Explanation

The diagnosis of AD as an explanation for Rose’s behaviours was extremely powerful in the Tanaka family. Maria, referring to the negative findings of investigations for her fainting spells, commented: “it doesn’t really matter now/ she has Alzheimer’s/” [IM: 88-89]. The diagnosis led to retrospective re-interpretation of other behaviours, such as driving accidents several years earlier, as evidenced by Maria’s comments: “I think it was – had to do with her- possibly the Alzheimer’s/ the confusion/ so/ ...and *that was *longer/ but..*we only see that *now//” [IM: 94-97]. Emerging behaviours also were cautiously attributed to Alzheimer’s. Maria, describing changes in her mother’s accounts of her family’s internment during the second world war, commented:

"a *bitterness, comes out...in *her, that she would..*never have shown/ ==we figured that *maybe that's part of the *Alzheimer's *too," [IM: 680-682]. There was clear uncertainty in that attribution, however, as she went on to question: "who am *I to say:./ that she should- but they never *had that- she never had:./ kind of those feelings before/" [IM: 686].

Despite the apparent acceptance of AD as an explanation for many of Rose's behaviours, there were small contradictions and questions about these interpretations. Maria's comments noted earlier about a return to childhood questioned whether such changes might be associated with normal aging in addition to Alzheimer's. Both Linda and Tom raised the issue of uncertainty surrounding the diagnosis of AD. Linda described the process of diagnosis as one of exclusion, noting that "Alzheimer's can't be..determined one hundred percent," [IL: 27] and that it's "something that could be diagnosed after death/" [IL: 30]. For Linda, however, the consequences of this uncertainty were that it took a long time to obtain a diagnosis; she neither overtly nor implicitly questioned the diagnosis itself. For Tom, in contrast, the significance of the diagnosis itself could be questioned:

I don't think uh..it's a clearcut uh..you know..uh..how
the doctors..uh..view the...the condition..and how I view it uh..obviously/
...I think we're both guessing..we're all guessing//

[IT: 64-66]

Whereas Maria and Linda discounted Rose's fainting spells as significant, in the context of the more powerful explanation of Alzheimer's, Tom considered them to be relevant, concluding that "I think..that's got to be part of the..problem as well/" [IT: 34]. Tom's questioning seemed in part to be associated with his awareness of Rose having "some good days, some bad days"[IT: 304], an awareness that was not evident in any of the

other family interviews. For Tom, a good day was “just a normal day” [IT: 313], while a bad day was “...repetitive questions/ the same question” [IT: 317]. Although he talked about this variability as “the strange thing about this disease” [IT: 306], he also considered the possible influence of Rose’s low blood pressure in accounting for it: “I think uh...the strange thing about good days and bad days has to do with the blood supply, you know? [omitted] in her case/ -she’s got low blood pressure,” [IT: 499-508]. For Tom, the unanswered questions surrounding AD made it a less powerful explanation for Rose’s behaviours than for other family members.

Diagnosis as Strategy

The separation of disease from person, coupled with the attribution of behaviours to disease, offers a strategy for accepting those behaviours without blaming the person, as exemplified in Linda’s comment: “but it’s..it’s {[heh-heh-heh] *Alzheimer’s/ like it’s *not like} she’s doing it/ ‘cause she’s for*getful, and *careless/” [IL: 344-346]. Family members talked about a variety of techniques that they used, with varying success, to help Rose to remember information or keep track of daily events: written notes, regular entries on the calendar, a daily schedule placed prominently on the kitchen table. Maria described specific ways that she tried to support her mother in conversation, some of which she had learned from a pamphlet about AD and then shared with her family:

when we were *challenging her at first/
um...like {[h] you don’t re*member that?}
and *so many times we would *say that/
uh...we *changed to *not saying that/
and then to *helping her/ give her *cues/”

[IM: 438-442].

These behaviours can be seen as accommodations to changes in Rose that were accepted because they were legitimated by the diagnosis of AD.

Maria drew attention specifically to the significance of the diagnosis in this regard with respect to her father:

I ended up calling/ and trying to get it faster/
 ' cause I just-...I just wanted to have a label,
 even though you don't want a label,
 but – y-y-you just- for my dad to know/
 so that/ he wouldn't get so angry at her all the time or/
 ..you know/ frustrated?

[IM: 194-200]

However, other comments, both of reported incidents and from Tom himself, suggest that although he recognized some of Rose's behaviours as typical of Alzheimer's, that recognition did not spare him from anger and frustration at those behaviours. From his children's perspective, his anger at Rose's behaviours (e.g., forgetfulness) implied that he thought she should be able to control it. All three children saw this as a source of tension in the family and attributed it either to differences in their understandings of Alzheimer's ("honestly/ I don't think he still understands/ what Alzheimer's is/ even though he says he does/" [IL: 325]) or to differences in family members' circumstances ("well he's stressed/ he has to do this all the time/ so when he lashes out it's because of his frustration/" [IM: 355]). For Tom, the diagnosis of AD did not help him to accept his wife's problematic behaviours because they could be attributed to the disease; for him, even after the diagnosis they continued to be a frustrating feature of his everyday interactions with his wife.

Diagnosis and Expectations

The diagnosis of AD, in addition to providing an explanation for Rose's behaviours, also offered a way of structuring expectations for the future, as seen in Maria's comment: "the more information I have the better/ because- ..in terms of dealing with her/ and how to..speak with her/ and..um what she's gonna- what she's gonna go through/" [IM: 22-24]. All her family members described changes in Rose primarily in terms of loss and decline, anticipating further losses including, explicitly, the loss of that which was of central importance to her life: the enjoyment of her grandchildren. For Tom, these expectations were coupled with the uncertainty of not knowing when they would occur; the result was that he and the children recognized that "we might as well...make things you know/ ..as uh..nice/..enjoyable for her/" [IT: 1121], going on to point out that "her kids in that respect are very very good" [IT: 1123].

It is possible that the expectation of declining abilities sometimes had the consequence of making it difficult to recognize unexpected achievements. Although Tom described Rose as having good days and bad days, when I asked him explicitly about any instances where she remembered something that surprised him, he replied: "yeah/ tha- that definitely has ...yeah/..happened/..um_ <3> but for the most part/ no/ that doesn't// if...very few...incidents like that/" [IT: 535-537]. At one point, he described an incident in which Rose forgot to meet him at an appointed place when they were traveling; however, he found her back at their hotel, where she had returned on her own. For Tom, the significance of the event was her forgetting the rendezvous, not her remembering the way back to the hotel.

In other cases, unexpected achievements were clearly recognized, but were difficult to account for in the context of declining abilities. Linda described an incident in which she helped her mother to choose an outfit to wear the next day to a special event, laying it out ready for her to put on. The next day, her mother came to the event, beautifully dressed (an attribute which Linda described her as always having had), but in a completely different outfit to the one laid ready for her. For Linda, there was a troubling incongruence between her mother's inability to remember choosing an outfit and her unexpected ability to find "the perfect suit, everything/"[IL: 1147], an incongruence which may have made her unsure of her assumptions about her mother's steadily declining capabilities.

Conversational Constructions

Analysis of the Tanaka family conversations in the context of the interview findings suggests several ways in which to explore how concepts of Alzheimer's are conversationally constructed. These include the construction of conversational behaviours as symptoms of Alzheimer's, strategic accommodations to those symptoms, and how Alzheimer's itself is represented in conversation.

Conversational Behaviours as Symptoms and Strategic Accommodations

Within the frame of Alzheimer's disease, conversational behaviours such as repeating oneself or forgetting new information take on the status of symptoms. In Rose's case, several family members mentioned her tendency to repeat herself as one of the first indications that there was something wrong. Throughout the family

conversations, there were numerous examples of this, exemplified in the following excerpt:

Excerpt 5.1

1. R: yeah/ *those are *nice/..eggs,..spill *oil -..*oil on the *pan,
 2. and um..some*time you *might have um..a nice po*tato left *over,
 3. like be*fore,
 4. and then um {[chopping sound on table]} *cut it in some *slices,
 5. M: mm*hm,
 6. R: and then *put it in the *pan, <2> then you *scramble some *eggs/
 7. and then the po*tatoes were all *warmed,
 8. M: =yeah,=
 9. R: =you = got some nice *oil on it/
 10. M: mm*hm,
 11. R: so it's not *stuck on the *bottom//
 12. ..and um...*yeah/ and then you put the *eggs/
 13. <2> *after you make sure that there's enough *oil/
 14. M:=mm/=
 15. R: =on =the *frying pan//...and *that makes it *nice//
 16. M:I *made that um/ <2> *egg roll, that you used to make?
 17. with the..*soy sauce, a little bit of *sugar,
 18. R: *oh yeah/ mm*hm,
 19. M: *Jim really *likes that/ he says {[h] *oh yeah/ it's *this/}
 20. R: I *haven't made *that for a *long long time//
 21. M: {[pp] mm*hm/}
 22. R: =={[pp] yeah/}
 23. M: {[pp] it's good//}
 24. <4>
 25. R: *something like that is *handy/ because as *long as you have *eggs/
 26. you could *scramble it, and uh..*put it in the *frying pan/
 27. but at the *same time/ if you *happen to have a leftover/
 28. ...*food that you could put it in *too/
 29. M:mm*hm,
 30. R: ..like *you know/.. sliced po*tatoes, or what*ever it is/
 31. <16>
 32. M:I *wonder where Tom will take you for *dinner tonight//
- [C/RM.3:13 20:58-21:34]

There are several features in this stretch of talk that support the interpretation of it as a symptom of Alzheimer's. First, even though Rose's description of the cooking procedure following the four second pause is less detailed than her first presentation, her failure to

make explicit reference to that presentation (e.g., “like I was saying”) suggests that she is not aware of having just talked about it. While these features themselves draw attention to the repetition, it is Maria’s response that suggests that, for her, it is a symptom of AD. Instead of drawing attention to it, or asking for an explanation of it, she allows a sixteen second silence and then shifts the topic.

A similar pattern emerges in examples of forgetfulness as a symptom of Alzheimer’s, as evidenced in these excerpts:

Excerpt 5.2

1. M: I’m going to be going to New *York at the end of this month//
2. R: mm/..*this month//
3. M: yeah//
4. R: =what/ by your =*self?
5. M: ={[I]in *August//} = no, with *Ann//
6. R: oh *I see, *Ann/= oh *she’s = back eh?
7. M: =*Ann and uh::_=
8. and we’ll be gone for *five *days//
9. R: mm*hm,
10. M: so *that should be =nice=//
11. R: =yeah//=

[C/RM.3.8:13:02-13:16]

After a little more description of the trip to New York, Maria switches the topic to an upcoming family wedding. Then:

12. M: *actually/ you know *what? it’s gonna be::_
13. I was thinking the wedding was *this weekend//
14. I’m going to.. New *York this weekend/ this *Saturday/
15. and then the wedding’s *after that//
16. so the *wedding’s another..*week and a half a*way//
17. R: oh//..so who’re you *going with//
18. M: with *Ann//
19. R: oh *I see, just the *two of you//

[C/RM.3.10: 14:35-14:50]

In the first segment, Rose’s comment “*she’s back eh?” allows little room for the possibility that she did not hear who was going with Maria to New York. However, the

falling intonation of her question in line 17 suggests that she is not asking for a reminder but rather for new information. Maria's neutral repetition of the information is in keeping with her description of recognizing forgetfulness as a symptom of Alzheimer's and not questioning or challenging it. However, an important aspect of that forgetfulness is Rose's apparent lack of awareness of it. When Rose herself acknowledged forgetting something, it was an occasion for supportive laughter, as in this example, when Rose left the dinner table to go to the kitchen for something:

Excerpt 5.3

1. M: what are you *looking for/
2. R: uh...*actually I don't *know what I'm looking for//
3. { [M, L, and T all laughing, not possible to hear if R is too] }
4. [omitted overlapped comments of L and T asking her to come
5. back to the table]
6. M: are you looking for *pickles,..maybe?

[C/RTLM.8.21: 14:50-15:00]

Attribution of behaviours as symptoms of Alzheimer's emerged in other ways in the Tanaka family conversations, in two instances affording opportunities for humour by deliberately applying the frame of Alzheimer's to Tom's actions. In the first of these, Tom himself set the stage for humour, with a laughing introduction to a short narrative during a dinner table conversation:

Excerpt 5.4

1. T: yeah/ *I gotta go to the *bank// {[laughing] you know *what?}
2. I think – I *went to make that de*posit?
3. {[laughing] <2> Alan's *cheque?}
4. [laugh] ...in a ma-..*bank machine?
5. {[laughing] <2>L.. *made out the slip/..and put the *slip through}/
6. and then ..*threw the **cheque away in the **wastebasket//}
7. {[all laughing] <5>}
8. T: *so I guess – [laughs]
9. M: {[still laughing] *maybe we should just -
10. <2> *change the *study to be on **you//}
11. T: {still laughing] *maybe it's *catching//}

- 12. L: *no:://
- 13. T: *anyway/
- 14. L: *wow/

[C/RTLM.8.38: 39:31-40:07]

The point of Tom's story, incorporating dramatic devices to build to a climax, was clearly to make a joke of this error in everyday activity. Maria, perhaps influenced by the presence of the video camera, made a teasing, implicit interpretation of his behaviour as a symptom of Alzheimer's, an interpretation which Tom himself endorsed. In conversation a few minutes later, Tom was interrupted as he began to make a comment about his grandchildren. A few seconds later, he took advantage of a break in the fast-paced conversation to start again:

Excerpt 5.5

- 1. T: you *know uh/
- 2. <4> I for*got what I was gonna ={[laugh]*say about it}//
- 3. ={[all laughing <3>}
- 4. M: {[still laughing, gesturing a camera lens moving to focus on T]}
- 5. **zoo::m/}
- 6. {[all continue laughing]}
- 7. M: {[still laughing] *what were you} gonna say about the *kids?

[C/RTLM.8.41: 42:46-43:02]

The structure of this excerpt closely parallels the earlier example of Rose's acknowledged forgetfulness: acknowledgement, followed by laughter, followed by a more serious effort to support the person in remembering. However, in contrast to that example, the teasing links to Alzheimer's, implicit in line 5 in the reference to the video camera, mark Tom's banking error and his forgetfulness as *not* attributed to Alzheimer's.

In other excerpts in which a family member framed Rose's behaviour as a symptom, differences emerged in others' interpretations. During a family dinner, Rose's offer of apple pie was rejected in favour of some persimmon for dessert:

Excerpt 5.6

1. T: *no no no no no/ *there's some uh...uh...some.uh...uh...per*simmon/
2. M: per*simmon? *oh::/
3. T: ==*sliced/ just a few *pieces//
4. *Rose/ could *you.. *get it?....if you don't *mind?
5. R: per*simmon//
6. M: per*simmon? they're - they *look like *oranges..kind of/
7. T: well *she's the one that *cut it/ {[p]and/}
8. M: yeah//

[C/RTLM.8.49: 49:06-49:21]

Maria's description in line 6 suggests that she interpreted Rose's "persimmon/" as a request for information. Tom's use of "well" to introduce his turn positions his comment in a particular way: Schifffrin (1987) suggested that "*well* locates a speaker as a respondent to one level of discourse and allows a temporary release from attention to others" (p. 127). In this context, Tom's comment moved from the discourse level of defining persimmons to a different level, as a comment on Rose's need for this additional information. As such, it also offered a defense of his expectation of Rose's ability to comply with his politely framed request. While he may not have been directly disputing Maria's interpretation, his response highlights differences in family members' expectations of what Rose could or could not do.

Differences in expectations contributed to differences in the extent to which family members provided unsolicited additional information to support Rose's conversational participation. For example, at the family dinner, Linda was asking her parents about a photo show they had gone to:

Excerpt 5.7

1. L: {[h] did you *go to that}...um/...*photo,...um...thing? with um/... *Bob?
2. ==that *photo..*gallery?
3. T: hmm? =oh *yeah/{[p]..yeah yeah//}=
4. L: =or..that *show? =

5. T: yeah/ yeah/
6. L: what was it *like/
7. T: it was *good/
8. ex*cept that this uh..=*lady/=
9. M: =it was = the in*ternment uh..*photos= ma//=
10. T: =*she=
11. just *talked and *talked/

[C/RTLM.8.30 23:10-23:26]

Maria's sidebar prompt to her mother presupposed that she might not remember the show, which she had attended with Tom. Such prompts occurred at several points in Rose's conversations with both Maria and Linda and suggest that they anticipated their mother's need for reminders. In contrast, Tom was more likely to probe for such need, as in this example:

Excerpt 5.8

1. <93>
2. T: do *you uh/ [clears throat] re*member who was *here to*day?
3. <3> to the *house?
4. R: oh/ <2> {[h] *wasn't that that} [*hankino]..uh..*lady?
5. T: [heh-heh] <2> *Barbara// mm,...now..*she said on *Thursday/
6. when [remainder omitted]

[C/RT.4.17.15:05-17:05]

The question form "do you remember..." is a relatively common way for a conversational participant to introduce a shared context in beginning a new topic. However, when used with a wh- constituent (e.g., "who" or "where") requiring retrieval rather than recognition of information, it can be seen more as a test than as a prompt. Tom's use of this form draws attention to his attempts to accommodate to the symptomatology of Rose's Alzheimer's in everyday conversation. In the interviews, he alone of all family members emphasized the variability of Rose's behaviour, with good days, when things were just normal, and bad days, marked by repetitive questions and not remembering. For Tom, this variability was part of everyday life, with the symptoms of

Alzheimer's apparent to a greater or lesser extent. In this context, his use of this particular form of the question "do you remember" allowed him not only to establish topical information, but also to check again for the symptoms of Alzheimer's against the ever-changing pattern of good and bad days.

In another example, Tom framed Rose's actions more explicitly in the language of symptoms. During the family dinner, Rose brought a cloth from the kitchen and began to wipe up sauce on the table, leading to this exchange:

Excerpt 5.9

1. T: Rose, *why don't you sit down and
2. M: ==*okay/
3. T: ==finish *eating here//
4. M: ==yeah/
5. T: she ..*seems to be ob*sessed with cleaning up//
6. L: {[ppp] it's *better than being.. *messy, ..like me,}
7. M: {[l] I *think I have that **too/ *I clean up a *lot//}
8. *John says/ {[h] *where's my..*where's my **glass/}
9. I say *oh/ I *put it in the *dishwasher already//
10. he says/ {[h] *I haven't even *finished my *stuff//}
11. <5>
12. so did you *hear about Lionel the *cat then?

[C/RTLM.8.21: 15:14-15:40]

Tom's use of the third person pronoun in line 5 indicates that he was describing Rose's behaviour to his daughters, rather than challenging her with it. This, coupled with the word "obsessed", suggests that he was framing her behaviour as a symptom, even though he made no explicit reference to Alzheimer's. His daughters' responses, in contrast, offer explanations that normalize their mother's behaviour. These responses do not necessarily indicate rejection of Tom's framing of Rose's behaviour, however, because they could mark instead Maria's and Linda's unwillingness to discuss such framing in Rose's presence, an unwillingness that is suggested by the five second silence and the clear topic

change that closes the discussion. To explore this explanation further, I turn now to an examination of references to Alzheimer's itself in the family's conversations.

Conversational Constructions of Alzheimer's

In all the recorded family conversations, there were only two instances in which Rose's Alzheimer's was discussed explicitly in conversation, although even in these, the diagnostic label itself was not used. In the first instance, Tom was talking about a friend who had called to ask after Rose:

Excerpt 5.10

1. M: what did *she want//
2. T: well/ =[clears throat]=
3. L: =*she used = to come by/ you know/
4. =the *office/ and take *Rose for- =
5. T: =I guess *she - you know - she- =
6. she - *word gets around that..*Rose's...about Rose's con*dition,
7. M: ..mm*hm,
8. <2>
9. did she *just want to know how she was *doing?
10. T: I *guess she ..just wants - ..*you know/
11. ...*wants to see how.. =things= *were?
12. M: =yeah/=
13. *you're feeling pretty *good though Ma huh?
14. R: *oh yeah/=uh*huh, =
15. M: =pretty good?=-

[C/RTL.M.8.27: 20:13-20:38]

Two points of interest emerge from this excerpt. The first is Tom's somewhat hesitant search for a referent to Alzheimer's, resulting finally in the euphemistic "Rose's condition". The second point of interest is Maria's question to Rose, framed in the language of physical health. This is particularly noteworthy given that, in the interviews, family members tended to frame Alzheimer's within a mind-body dichotomy, sparing physical abilities but affecting the mind. In view of that framing, Maria's question to her

mother can be interpreted as redirection away from “Rose’s condition” to her physical health, which everyone acknowledges to be good. As such, it offers further evidence of reluctance to engage in explicit reference to Alzheimer’s in Rose’s presence.

The second possible reference to Alzheimer’s occurred later in the same conversation, when Tom was talking about plans for an upcoming trip with Rose:

Excerpt 5.11

1. T: he *knows/...that Rose..*sometimes has *memory problems//
2. M: mm*hm/
3. T: and *so I *said/ I’d *like to have somebody *with me/
4. L: yeah/

[C/RTLM.8.63: 1:01:13-1:01:20]

Here again, Tom avoided explicit mention of Alzheimer’s, alluding instead to Rose’s memory problems.

Taken together, these examples suggest that, although all family members acknowledged openly Rose’s diagnosis of Alzheimer’s with clearly articulated understandings of what that represented, they nevertheless tended to avoid explicit acknowledgement of that diagnosis in conversations that included her. References to Alzheimer’s were oblique (as in the references to the study and the camera), euphemistic (as in “Rose’s condition”), or described in terms of Alzheimer’s most salient symptom (as in “memory problems”). This avoidance suggests that both sensitivity to the stigma associated with Alzheimer’s in public discourse and a desire to protect Rose from that stigma also had a role in shaping family conversations. The tensions inherent in these conflicting understandings become apparent in examining conversational actions in the context of interview comments. For example, both daughters in the interviews referred to the importance of the diagnosis of AD in facilitating understanding of problematic

behaviours as symptoms, including seeking a diagnosis to help their father cope with such behaviours. Yet, in conversation, both resorted to normalizing explanations when their father interpreted Rose's behaviour within the framework of disorder. The point here is not to weaken either explanation by highlighting the inconsistency but rather to illustrate how competing goals are framed and accomplished in different contexts. This can be explored further by shifting our focus from understandings of Alzheimer's disease to an examination of changes in family life associated with Alzheimer's.

Alzheimer's in the Family

Interview Representations

Solidarity and Mutual Support

A strong theme throughout the Tanaka family interviews was that of family solidarity, reflected in numerous ways. Family members all lived within a few miles of each other, and all described regular visits with each other, both individually and at frequent family get-togethers, sometimes centering around special occasions, often centering around meals. Family members supported each other in business and in daily life: Rose had done book-keeping in her children's businesses and provided child-care for her grandchildren, Colin helped Linda with her book-keeping, the family together helped when someone moved to a new house.

In addition to descriptions of the many ways in which family members spent time together, connections between family members were highlighted both inter- and intragenerationally through descriptions of shared traits. For example Linda, talking

about her father writing out a daily schedule for Rose, commented: "well you should see all of us kids/ we all carry note pads, [omitted] we got it from him//'" [IL: 8-12].

Similarly, when talking about the family getting together, she remarked "because..all of us love to eat and cook//..and Rose was – you know/ Rose's the reason why" [IL: 784-786]. Rose herself attributed her own love of cooking to her mother: "my mother was a good cook/ yeah/ she was very very good//.. and she taught me everything/ you know?" [IR: 1008-1010]. She drew further connections between generations in describing ways in which Maria takes after her (Rose's) mother and her aunt, while Linda takes after Tom's side of the family, a comparison that Linda herself echoed: "I'm kind of like my dad that way" [IL: 889].

The importance of connections across generations was apparent at several points throughout Rose's interview. The strength of the grandparent – grandchild relationship was inherent, not only in Rose's comment: "you know how they love to play with their grandparents" [IR: 358], but also in her descriptions of her own grandchildren and the obvious importance they have in her life. Rose also implicitly linked the grandparent-grandchild relationship to a broader sense of heritage in talking about her children. She commented that "because our parents have gone a long time ago, they're – they don't speak too many Japanese/" [IR: 318], although her father was alive when they were young: "the children loved him/ they used to play with him,[omitted] and he tried to speak as much..easy Japanese language to the kids//'" [IR: 366-370]. In the interviews with the three children, the link to Japanese-Canadian heritage was explicit only in the interview with Maria as she talked about her mother sharing stories with her of their family's internment. As noted earlier, Maria questioned the extent to which her mother's

emerging bitterness could be attributed to Alzheimer's, contrasting it with an acceptance that she associated with her Japanese-Canadian heritage: "the Japanese Canadians..had this term called [she *ga tuh ga *nye]/ it can't be helped/ it just- and they let it go, and they moved **on//'' [IM: 687-688].

The theme of family solidarity was maintained in participants' descriptions of changes in family life that they associated with Rose's having Alzheimer's. All three children commented that, while they had always been close, their mother's Alzheimer's had brought them even closer; one did question, however, whether perhaps it was more that "this is just the new focus?" [I3: 472]⁷ In the children's interviews, the dominance of the pronoun "we" was striking. Although rarely explicitly defined in those interviews, "we" most often appeared to refer, in the context of Alzheimer's and family life, to the three children, particularly as they each described how they shared with each other their concern about changes in their mother and together planned ways for coping with those changes, exemplified in this comment: "Maria, Colin and I now/..purposely schedule times, where we're spending -..so that we don't overlap our times?" IL: 421-422].

While all three siblings used "we" frequently in talking about family life, there were also clear individual voices in the three interviews. Each acknowledged their individual perceptions and reactions with the pronoun "I", as in Colin's comment: "I knew that there was something wrong with her before/ she was actually - you know/ actually diagnosed/" [IC: 21-22]. Maria, talking about the growing awareness of her mother's problems prior to diagnosis, drew attention to differences among the siblings,

⁷ Instead of an initial, number codes were assigned to participants only for those quotations where all three children made similar comments. The use of the anonymous code here indicates that this comment could have been made by any of the three, avoiding attribution to any one in particular. Decision to code this way was a choice on my part, not at the request of the participant.

remarking that: "I think my brother, and my sister/ were a little bit more ahead than me/" [IM: 400], adding that "then..when I realized..it..there was something definitely wrong,.. I kind of took the reins/" [IM: 411]. Each of the three children acknowledged their own and their siblings' individual contributions to supporting Rose and, indirectly Tom. Maria described herself as being the one "to do more family holidays" [IM: 3366], Colin doing "amazing stuff with..his kids/ with her/" [IM: 367], and Linda being the one "who takes the day to day stuff" [IM: 368], having Rose come in regularly to her business. Linda, too, talked about their individual, but equal, participation:

there's just times where/..*somebody's got to step up to the *bat/
because one of us is busy, or whatever?
but there's *never the sense/
*oh/ *so and so's doing..not *pulling their *share/ it's *never the case//
[IL: 1190 – 1996]

She contrasted their circumstances with an imagined scenario of being alone with siblings out of town:

I don't know/ *how..you would be able to com*municate/
how much *time it takes, or what it takes *out of you?
..or the lo- *you know/ what you f-..must *feel?
[IL: 1174-1175]

Her comment draws attention to the ways in which their equal participation in supporting their parents is also a source of support for each other.

The interpretation of "we" as referring to the children (rather than the children and Tom) in their three interviews is indicated also by comments such as Linda's: "we definitely did/ ..keep in touch/..and..define what we were gonna do/..now..what we *didn't do/ was to include *Tom in a lot of that" [IL: 361-364]. In the context of Alzheimer's and family life, however, the theme of family solidarity is complicated by tensions between the all three children and their father. All three children referred to

these tensions, both as a consequence of differences in how they interpreted changes in their mother's behaviours:

we pushed my dad to get her checked out with the family doctor..and even at that point he would say no/ she's fine/ sh- they'd do the memory test/ and we'd say..no/ there's something- we fought against ..my father for awhile/

[I1: 126-128]

and as a consequence of differences in how they responded to those changes:

we know it's difficult to be with her for a ..a whole day/
or a few days in a row/ so we don't know exactly what's going on but-
..we-..I guess {[dc] the kids don't feel that he's_}
<3> kind of handling the..situation very well?

[I2: 327-332]

The mitigating explanation given in the first phrases, together with the hesitations, rate change, and rising intonation in this quote all combine to suggest the speaker's discomfort in criticizing Tom's behaviour. Similar discomfort and allowances for Tom's perceived reactions occurred throughout the children's interviews and themselves point to ways in which the children continued to support their father, even when they did not agree with him.

Tom acknowledged his children's support explicitly at several points throughout our interview, both collectively: "the kids have been *very very ..*very supportive/" [IT: :231], and individually, as he too described how each spent time with Rose in their individual ways. However, there is some evidence that, while the children describe themselves as supporting both Tom and Rose, Tom, in talking about that support, saw it primarily in terms of Rose: "her kids in that respect are very very good/" [IT: 1123]. He even questioned whether, possibly, they were "over concerned" [IT: 227] about him. Nevertheless, in talking about looking after Rose, he too used "we", referring to himself

and the children: "I think we all recognize/ well we might as well...make ..things *you know/ ..as uh..nice/..enjoyable for her/ as..*you know/" [IT: 1120-1121]. The theme of family tensions was not apparent in Tom's interview

Changing Family Roles and Attributed Reactions

Another strong theme that emerged from the Tanaka interviews was that of changing roles that family members associated with Alzheimer's. Again, with the exception of Rose's interview, there was remarkable consistency in descriptions both of individuals' own and others' changing roles and of their reactions to those changes. All four family members identified the additional stress for Tom in caring for Rose, with Maria explicitly identifying a change in his role, identifying him as "more of a caregiver" [IM: 347] and Linda commenting: "I mean it's obviously *he has to carry the burden" [IL: 416]. Tom himself described his role more in terms of taking responsibility for Rose than in terms of care: "I've got everything planned out for her" [IT: 799]. There was some evidence also of his effort to maintain his own long-standing roles in the presence of his wife's Alzheimer's. In the interview with Maria, I learned of Tom's role as scientist when, referring to earlier years when Rose's fainting spells were being investigated, Maria remarked: "me and my dad be-..my dad..being a scientist/ so we wrote down when she had fainted," [IM: 73-74]. In my subsequent interview with Tom, when he was questioning the reasons for Rose's good days and bad days, he commented:

I'm more interested I guess in – in the uh- org..org-the organic/
the- the..cellular/ [omitted] and maybe from that point of view/
I'm looking at her/..not necessarily as a husband/ [omitted]
..studying..quite often studying/
without her really knowing what I'm – that I'm..studying her//
[IT: 479-493]

There is a poignancy in this reference to his scientist self in Tom's subsequent comment:

"you know/..but uh..nothing **I can do/ ..it's just out of curiosity/ {[p] and nothing else/}" [IT: 495].

In talking about changes in their own lives associated with Rose's Alzheimer's, the three children spoke extensively about changes in their routine activities, describing how their joint efforts to organize their schedules to ensure regular support for both Rose and Tom led to a shift in focus and in the way they spent time together. However, they only rarely referred explicitly to individual or family roles. One such instance was in Maria's description of how Colin's reaction to his mother's Alzheimer's differed from hers and Linda's:

[ac, p] we just go okay/ this is what's gonna happen/
we do this and this and this/ this is what we can expect/
for *him/..being the baby of the family/
and I think..now he has to be more a parent, it's hard for him//
[IM: 389-390]

Maria's analogy of the shift to parent in the family (interpreted here as family of origin) appeared elsewhere as she described the time that Rose spends in Linda's business, formerly as working time, now as "kind of a babysitting time" [IM: 246]. Colin, in contrast, did not describe his reaction in terms of role change, but rather as "an eye opener" [IC: 32] as he learned more about the disease and began to realize what "other people and families are going through" [IC: 30] and, presumably, what he might expect his family to go through as well.

A significant theme in the interviews with the three children was Rose's loss of ability to continue with activities of major importance to her. These included caring for

her grandchildren and, particularly in Colin's interview, cooking for her family. In describing that loss, he drew attention to his perception of her feelings:

and so she can't cook anymore/ I think she feels..very very helpless/
and she looks-..if you see her/..in that situation/
she looks very helpless/ she's on-..sort of on the outside/
looking in as the kids are preparing stuff/
and she's asking whether she can help/
and ..we try to get her to help/ as much as we can/

[IC: 577-585]

His description is in marked contrast to Rose's comments about her children now cooking dinners, a fact that she volunteered herself:

they all come over, and bring their – they *even got the **food all cooked//
[omitted] I'm quite happy at them/ I didn't force them to bring the food,
um:...my kids are funny- they enjoy it/ like you know,
so uh..I don't have to uh..pressure them or anything/

[IR: 714-724]

While acknowledging and appreciating that her children now had a greater role in family cooking, Rose did not show any awareness of her own loss of that role, describing other meals that she had cooked for other people and talking about her own love of cooking. Similarly, while her family was keenly aware of her inability to reliably look after her grandchildren, she herself was unaware of that, reportedly saying to Colin recently: "well if you have things to do/ I can look after the kids/ and you go off and...do your thing/" [IC: 693-694].

Rose also talked about herself at points as the children's mother, describing how, for example, upon learning that she had Alzheimer's, she "explained to the children/ that – don't be afraid to ask me, ..you know, if I'm...very ...if I'm very upset about it/" [IR: 53-54]. In contrast, Linda, talking about how her relationship with her mother had become very one-sided as a consequence of Alzheimer's, related telling a friend who was

missing his mother, “you know what? I miss my mom too/” [IL: 1188]. Her comment draws attention to her use of “mom”. As a result of their having been in business together, Linda generally referred to both parents by their first names. In the entire interview, there was only other instance in which she referred to Rose as “mom”. When Linda was talking about her mother at the social event where Rose had chosen her own outfit, she mentioned that a waitress had spilled coffee on Rose’s dress, adding: “my mom was so nice about it/ [omitted] that’s her reaction” [IL: 1148-1149], suggesting that, in this instance, she saw Rose maintaining her role as “mom”.

Coping Strategies and Ethical Challenges

For Tom and all three of the Tanaka children, changes associated with Rose’s Alzheimer’s presented ethical challenges as they worked out ways to cope with those changes. In all four interviews there was evidence that each individual initially resisted the possibility of Alzheimer’s and the decision to seek a diagnosis. This resistance was in part due to unwillingness to acknowledge the possibility: for example, Maria commented: “I knew something was wrong/ but I just thought/ {[h,p] {[\\ah::} you know what::?}..I don’t really want to deal:: with it yet” [IM: 402-403]. However, there were also ethical dimensions. Tom described his discomfort at looking through Rose’s papers after her failure to pay their income tax, in order to find out what was being left undone: “even if it’s my wife/ she has a certain privacy/” [IT: 103-105]. A comment in the interview with Colin draws attention to an ethical concern: “I started to monitor..more.. closely say {[ac] than the rest of the family?} because...I had my daughter to think about/” [IC: 173-175]. For Colin, his reluctance to bring his concerns to the attention of others in his family was in conflict with his concern for his daughter in being looked after by Rose.

This conflict was even stronger when all three children agreed that Rose could no longer look after her grandchildren, while at the same time all being aware of the importance of that role for her, as Maria explained: “well/ she loved Alison so much/ ..you know, to take that away was gonna be really hard/” [IM: 100]. Maria went on to explain how Rose had a major fainting spell, “which was perfect/” [IM: 101] because they could use it as an excuse to suggest that it was no longer safe for her to look after her grand-daughter: “when in fact...it was more her memory thing” [IM: 107]. The family’s apparent relief at having a reason other than Alzheimer’s to justify taking away Rose’s child care responsibilities points to the complexities of the family coming to terms with a diagnosis of Alzheimer’s. The family did not attempt to keep the diagnosis from Rose; Maria in particular described talking with her mother about it, although she, as well as others, questioned the extent to which Rose was aware of the implications of the diagnosis. This could in part explain why they perceived a physical problem to be, at least for Rose, a more acceptable justification for giving up a key role in her life. On the other hand, the physically-based excuse also allowed the family to avoid confronting Rose with the implications of her diagnosis. Yet, it could be argued, in avoiding discussing those implications with Rose, family members inadvertently contributed to her lack of awareness. Over time, at least one family member did begin to cite Alzheimer’s as the reason for not doing certain activities. When Rose offered to look after Colin’s children so that he could go out, he responded: “you can’t/ because you’ve..got Alzheimer’s disease/”, linking it to her behaviour: “you’re very forgetful/” and “you’re not operating/..quite {[heh-heh] properly/}” [IC: 696-698], to which Rose reportedly replied {[h] oh no/ I’m fine/} [IC: 698].

In talking about Rose's awareness, or lack of it, of having Alzheimer's, family members commented that sometimes she was "covering up" [IL: 696], suggesting both an awareness of having Alzheimer's and a wish to hide it. Maria commented that: "she's smart enough to know::/ that she has to be..careful of what she says now/ so she can appear to be still..normal/" [219-222]; Linda made similar observations: "I do notice that she does...hide the fact that..she doesn't remember//" [IL: 982]. Colin, too, described how: "she tries to hide as much stuff as possible/" [IC: 666-668], but he also perceived inconsistencies in his mother's awareness:

sometimes I think that she *really thinks that there's - *you know/
she standing in the kitchen wondering *why/..she's not *cooking/
and she *knows/ *oh I've got..*you know/ some sort of -
I just can't *do it anymore/ and *other times/ I..I think that..she'd-
*she thinks there's nothing *wrong with her/"

[IC: 668-674]

Family members were to some extent all concerned with helping Rose to appear normal. In describing Tom's tendency to censor Rose's comments, Maria linked it to protecting her: "if it's a guest,..he kinda protects her, and makes sure, and..we actually all do//" [IM: 772-774]. At the same time, there is an undertone of protecting themselves, as well as Rose, as in this comment describing how Rose's repetitive story-telling: "kind of embarrasses us/" [I1: 669].

Another ethical challenge inherent in protecting Rose versus confronting her with her changing abilities centered in the issue of truth-telling. Tom described having, sometimes, "to be kind of brutal" [IT: 676] when Rose insisted on doing things that the others could not accommodate, telling her "you're really not needed there//" [IT: 677]. His description of this truth-telling as "brutal" is in keeping with the family's desire to

protect Rose; at times, the alternative strategy of lying was preferable: "I've *learned a few things from Maria/ she says/..*lie to her// [heh-heh] *white lies/" {IT: 434}. For example, family members began to withhold telling Rose about upcoming events, in order to avoid having her ask repeatedly and become anxious about them. However, this strategy led to further deception in response to Rose's anger at no one having told her: "[heh-heh] well we did// you just forgot/ [heh-heh]" [IL: 923-924]. The speaker's laughter marked her discomfort with this reported deception, and it was framed as an ethical issue by her accompanying comment: "I'm not sure this is a good thing" [IL: 921]. Similar patterns were noted in all four family members' references to using "white lies" as a coping strategy, suggesting that, even though it was a strategy all agreed on to at least some extent, it was one that was not comfortable. In an interesting parallel, Rose herself described not telling older family members that she was going away "because..they might – uh..feel so lost during that couple of weeks//" [IR: 121], explaining to them instead on her return that she had been too busy to call. While there was no evidence at all in the interview with Rose that she was aware of her family's use of this strategy for her, her comments do suggest the possibility that, in principle at least, she would consider it acceptable.

Ethical issues also arose in family members' efforts to enable Rose to maintain as much independence as possible while at the same time accommodating to her deficits. Throughout the interviews, there is evidence of Rose's family working individually and together to support her in maintaining familiar roles as best she could. For example Linda, describing her mother's activities at her office, commented: "you know what? she feels useful here// in fact/ in her mind/...she feels like/..I can't..do without

her?...and:...it's actually the opposite?" [IL: 213-215], going on to explain that "it takes more of my time and energy/ to watch what she's doing/" [IL: 216]. Despite these extra demands, Linda, like other family members, described finding activities that her mother could still do "...so she knows/ that I appreciate it" [IL: 229]. At the same time, family members were all acutely aware of their own part in her loss of independence. Linda, for example, talking about Rose's loss of independence, commented: "*we're making all her decisions for her now/ {[p]which is kinda sad//}" [IL: 174]. When I asked Linda if Rose seemed to notice that, she went on to describe the incident in which she helped her mother to choose an outfit for a special event the next day, only to have her mother appear in something completely appropriate that she had selected herself. Implicit in Linda's description of this event, and her own reaction to it, was her concern about her own part in her mother's loss of independence. Concern for Rose's well-being was frequently in conflict with respect of her autonomy.

Conversational Representations

While the family interviews offer insight into how each member perceived changes in family life associated with Alzheimer's, it is through analysis of their conversations that we can learn how those changes are performed in everyday life. The changing roles described by each individual present interactional challenges and tensions that must be negotiated in conversations if family solidarity is to be maintained. Three themes in particular that emerged in the interviews provide a framework for exploring such negotiation. The first of these themes focuses on changes in the parent-child relationship, highlighted by Maria's comment about her brother's changing role in the family. The second theme concerns cooking, described by several participants as an

important aspect of Rose's role in the family. The third theme is associated with the tension inherent in balancing care for Rose against respect for her independence.

Changing Places

In the only conversation including Colin and his mother, both were engaged throughout in looking after his two young daughters with few, if any, opportunities for uninterrupted talk between the two adults. As child care was the predominant activity during the half hour recording, Colin's conversational positioning as both son and father offers a unique opportunity to explore how, from his special place as youngest in the family, he moved also to being more of a parent to Rose.

Although it is not clear how long Rose had been at Colin's house prior to the recording, his first comments suggest that her visit (or at least, going to swimming lessons) was linked to Tom's absence from home.

Excerpt 5.12

1. C: so *you're going to come to *swimming lessons with us//
2. R: ..oh/..is *that right?
3. C: =yeah/=
4. R: =*last = (one), where- {[h] where *was it} that we had (all that)//
5. *right by that uh..little_
6. C: ...um:: *Lynn Phillips *pool//
7. R: yeah//
8. C: 'cause *dad's not gonna be home/ so – [sound of musical toy]
oh *Alison/..*no no/

[C/RC.7.2 0:54 – 1.10]

Colin's opening comment, with its final fall in intonation, was framed, not as an invitation, but as a statement signifying a decision that had already been made. The introductory discourse marker "so" suggests a reference to some basis for the decision, but it was not found in preceding talk – rather, it followed in Colin's explanation given in

the last line of the excerpt. Rose, with her rising intonation in questioning the statement, seemed to be seeking confirmation rather than challenging the decision itself. Her subsequent reference to a previous swimming lesson suggests her acceptance of going to swimming lessons with Colin's family as a familiar activity. Nevertheless, Colin offered an account to justify a decision that apparently precluded any choice for Rose other than compliance, thereby marking the excerpt as an example of the decision-making for another that is more commonly associated with the role of a parent than that of a child.

While Colin's framing to Rose of her going to swimming lessons may be suggestive of one that might be used by a parent with a child, his framing of that event to his daughter supported Rose's position as grandmother:

Excerpt 5.13

1. C: *Alison/ are you ex*cited?
2. *Grandma's coming to *swimming lessons/ with *you/
3. A: {[]**yeah:::} a{[]*gain:::}
4. ...'*member?...*she came swimming wi-
5. [hh]... a*nother day *too/ '*member?

[C/RC.7.6: 3:13-3:23]

Colin's reframing invited his daughter's enthusiasm and in doing so moved Rose's going to swimming lessons from being a necessary decision in the care of a person with Alzheimer's to being an opportunity for a special treat for children with their grandmother.

The alternative framings of Rose as a person who herself required at least supervision versus as a parent who might participate in the care of her family emerged in other parts of the conversation. For example, after Colin identified a shirt as belonging to Alison, Rose began to do up its buttons, leading to this exchange:

Excerpt 5.14

1. C: *don't do the *buttons up =mom//=
2. R: =oh/ =...just..as *is?
3. C: {[pp] yeah//}
4. R: {[ppp] *okay//}
5. {[no conversation but C telling S several times not to touch something
6. <34>]}
7. C: *mom?
8. R: hmm?
9. C: *don't do the *buttons up//
10. R: oh/..don't *do it/ eh?
11. C: {[p] yeah/}...well *just 'cause-...=we have to..have=un*done-
12. R: =it's *hard to// =
13. C: well *no//...see we have to *undo them/
14. =to put the- = *clothes on/=on the =*baby?
15. R: =oh- oh *I-= =*I see/ = *yeah//
16. C: on *Alison?
17. R: mm*hm//
18. C: so it's *no use doing them *up/..because we have to *undo them//
[C/RC/7.9: 5:04 – 5:55]

Rose did not contest Colin's first instruction; instead, she confirmed it first with a question and then with agreement. Colin's subsequent repetition (in exactly the same words as the first instruction) suggests that he assumed that Rose had forgotten it during the intervening 34 seconds; her use of "oh" to introduce her response in line 10, marks it as new information for her (see Schifffrin, 1987; Davis, 2005a). Nevertheless, he followed his repeated instruction with an account to justify it, attending not only to informational issues but also to politeness needs, evidenced in his use of discourse markers. One identified function of the discourse marker "well," particularly in utterance-initial position, is as a "face-threat mitigator" (Davis, 2005a, p. 132; Jucker, 1993). Colin's use of "well" followed by "just 'cause" is consistent with this function of mitigation, as it softens the implied need for an explanation. Rose, in offering the overlapped completion "it's hard to//", signaled acceptance of Colin's repeated instruction, although his subsequent comment, prefaced by "well" to mark contradiction, corrected her

assumption. While Colin's instruction and repetition to his mother might seem to have undermined her authority as a parent, such undermining was mitigated by both the account he offered and his correction to her assumed account: she deserved not just an account, but also a true account.

Together, the preceding excerpts illustrate how Colin, engaged in looking after a toddler and a preschool-aged daughter, moved between speaking with and of Rose as a mother and grandmother versus as another family member needing supervision. These contrasting positions are captured in the ambiguity of the following:

Excerpt 5.15

1. C: 'kay *Alison? it *looks like *Sally's not gonna go *down for awhile/
 2. so *anyway/ *I'm gonna go in and see if I can *calm her *down//
 3. R: *sure//
 4. C: *you guys can just *keep on *playing//
 5. {[h] *why don't you play a game of..your..coloured *card game//}
- [C/RC/7.19:21 – 19:30]

In this excerpt, Colin had just come back to where Rose and Alison were playing a board game together. Although he directed his opening comment to Alison, it was Rose who endorsed his decision to go back to the baby, positioning herself as an adult who understood his need to do so. The ambiguity lies in the next utterance which, with its address of "you guys", suggests an alignment between Rose and Alison that could be taken either to emphasize the solidarity of the two engaged together in a game, or as a signal of their equality with neither being asked to take responsibility for the other. Within the context of the larger conversation, both interpretations are possible, so that perhaps in this excerpt they are in evidence at one and the same time.

The Family Cook

The theme of cooking emerged at several points and in several ways in the interviews with participants, with everyone, including Rose, alluding both to the significance and to the gradual diminishing of her role as cook for her family. The importance of this role was emphasized in conversations, as family members talked about food, planned meals, or discussed recipes, not surprisingly as six of the seven recorded conversations were associated with participants eating and drinking together. Thus, cooking offers an excellent example for exploring the conversational construction of role change associated with changes in meaningful activity.

Two conversational excerpts cited earlier (5.3, in which Rose forgot what she had gone to the kitchen for, and 5.6, in which she did not know what a persimmon was) illustrate Rose's difficulty in participating in mealtime preparation. At the same time, they illustrate both the ways in which her family supported her ongoing participation, and the ways in which they limited it. While these examples shed some light on how the family coped with Rose's difficulty with cooking and meal preparation as an activity, there are several examples that go beyond this to reveal how family members found other ways to support Rose in her role as cook.

The first of these examples occurred in a conversation between Maria and her mother, in which they were talking about children choosing to eat "junk" food, leading to this exchange:

Excerpt 5.16

1. M: *I don't think any of *us ate that much,
2. ..like *that when we were growing up,
3. R: I *don't be*lieve in children *eat'n those/
4. M: yeah/

5. R: um...*oil-fried um...*chips//
 6. M: yeah//
 7. <2>
 8. *I don't remember eating *any of that stuff/ so,
 9. <2>
 10. un*less we were at someone *else's/ {[heh-heh] Auntie *Sarah's or-}
 11. R: {[ppp] hehehe}
 12. <2>
 13. M:but even *there we didn't get..that *actually/
 14. R:={[pp]yeah/}=
 15. M:=-.when = you *think about it it was more -
 16. {[pp] we had - we *ate pretty *well//}
 17. <3>
 18. M:do you miss *cooking?
 19. R: {[h] no not} *really,
 20. M:yeah/ ..it gets - I guess after *years:: of cook=ing, =
 21. R: =yeah/ =
 22. M:it gets kinda *boring/ uh?
 23. R: 'cause *just Tom and *me::,
 24. M:yeah/
 25. R: and um.. so *that doesn't bother me at *all//
 26. M:={[ppp] no} =
 27. R:={[ppp] mm*hm,}=
 28. M:..no/ I'd *like it..if someone -...if *Jim took over the *cooking//
 29. R: .. yeah {[h] *he looks like} a cooker *too,
 ' cause I guess - *he's been alone *too/ hasn't he?

[C/RM/3.1318:36 - 19:36]

Maria's first comments linked back to a past in which Rose, as family cook, was responsible for what her children ate, a move that gave Rose the opportunity to assert one of her values in that role. Maria endorsed those values by recalling that "we ate pretty well". This acknowledgement of the importance of Rose's role as cook allowed her mother to consider the question about missing cooking within the context of that acknowledgement, framing it as a change in activity that did not necessarily mark a change in role. Maria followed up on her mother's unelaborated response in terms that supported the former interpretation, offering an explanation of why her mother might choose not to cook, an explanation that Rose accepted in her next response. The entire

exchange allowed Maria to talk with her mother about her present circumstance of no longer cooking, while at the same time allowing her mother to maintain herself in her role as a cook, evident in her final comment about Jim: "he looks like a cooker too."

Respect for Rose's long-standing role as family cook, balanced against her increasing difficulty in actually cooking, was reflected also in negotiations around planning special family events. The following excerpt took place after Linda introduced the topic of Christmas, then reminded her parents that Colin and his family would be having dinner with his wife's side of the family (See Appendix E, Transcript 1):

Excerpt 5.17

1. M: so *we're gonna -
2. L: well - {[sounds of serving out food] <5>*we thought/}
3. ...we'd come *here for Christmas dinner,
4. R: mm*hm?
5. L: {[l. p, ac] like we *usually do,}
6. R: yeah/
7. L: =inste=-
8. T: {[to M, reaching for something]=may = *I have a_ }
9. L: in*stead of having... *turkey/ <2> we'll have *ham//
10. ..'cause it's *easier?
11. R: yeah/.. **ham is nice// you get - you *know? you get a.. a-
12. M: mm*hm/
13. R: ..it's...uh..with the *skin *on,
14. L: yeah//
15. R: ..un*less the butcher *takes it/
16. I *don't think - you- *you know how you-
17. M: =you sc=-
18. R: =you = put the *cross on?
19. M: yeah/ you *score it?
20. L: yeah//
22. R: *score it? and then you *make a little..uh.. *thing/ with the um.. *sugar::_
23. and =um_ =
24. T: =o*kay =you guys/ *help your=*selves//=
25. R: =..what = =*ever= it is//
26. M: =sure//=
27. like a *mixture// =yeah// =
28. R: =*mixture,=
29. T: help your*self/ you guys,

30. L: yeah/ {[f] so I *thought what I'll *do/
 31. is.. =*cook it, at- =
 32. T: {[moved away from the table} = I *guess I'll=put some *more in//}
 33. L: {[~] *home::,}
 34. R mm*hm,
 35. M: yeah?
 36. L: and then I'll bring it *here//
 37. R: {[pp] oh *oh *I see}
 38. T: {[back at the table][sighing]=oh *yeah::/=}
 39. M: =yeah/ =
 40. T: =so are *you gonna have - =
 41. M: =and *I'll do:: = the po*tatoes mashed, and maybe some -
 42. like a *squash/ or something like *that//
 43. L: {[sound of tea being poured][p] thank you/}
 44. R: *I've got two squash now/
 45. M: {[p] you want some more *mushrooms mom?
 there's *lots of *mushrooms here/

[C/RMLT/8.13: 10:11 – 11:07]

There are numerous points in this exchange that point to it as a negotiation. First, Linda's reminder about Colin's plans appeared to be a presequence (Schegloff, 1990), peripheral to the main point but useful in setting it up. Maria, who had not participated up to this point in the exchange, began to take over in the first line given here, but then broke off to allow her sister to continue to develop her point. This move emphasizes the sisters' solidarity in supporting their mother, pointing to either a pre-planned strategy or to a shared set of goals for the interaction. Throughout the discussion, Tom was more concerned with the current meal than with planning a future one, (except in line 40), suggesting that Linda's careful arguments were intended more for her mother than her father. She presented the plan as a proposal, ("well *we thought"), linked it parenthetically to past tradition ("like we usually do"), then moved to the proposed change from turkey to ham, with a justification ("cause it's easier.") Although her presentation anticipated the possibility of disagreement, Rose immediately agreed with the proposal, at the same time reinforcing her own role as family cook by contributing a

22. M: well you know *what? you *probably just need *this//

23. L: *this is **fine//

24. M: yeah/ *this was a *really good **sauce//

[C/RMLT/8.44: 44:58-45:31]

While his daughters' compliments and suggestion that Tom should make the dish for his siblings offered one form of support, it was their more critical discussion of the best sauce, ending with endorsement of the one he had used, that acknowledged him in the role of cook.

Rose, although at the table, did not take part in this discussion at all, possibly because no one directed comments specifically to her, nor invited her participation in other ways; in any case, this excerpt focused on Tom as cook. Nonetheless, other instances marked "cook" as a role they could share. In a dinner conversation between just Tom and Rose, they engaged in similar evaluative, albeit shorter, discussion:

Excerpt 5.19

1. {[sound of eating] <45>}

2. R: =I- =

3. T: =I = *guess I - I should've uh

4. {[chewing] <3> *boiled the *beans longer/

5. R: I *think you have to...pan *fry it again//

6. T: yeah//...*it's okay,..just *chewy/

7. <3>

8. T: *hmm//

9. {[sound of eating] <30>}

[C/RT.4.19: 17:22 – 18:53]

Tom's remark, framed as critical comment but also as a guess, invited Rose's response, both acknowledging her expertise and her right to offer advice. Nevertheless, by prefacing it with "I think", she framed her own comment as a suggestion, showing respect for his role as cook.

These excerpts, taken together, illustrate how, in negotiating the activities of cooking, the family was able to support both long-standing and emergent roles among its members. The conversational construction of “a cook” could be maintained somewhat independently of the everyday activity of “who cooks”, allowing the family to minimize the loss of that role for Rose and simultaneously to support Tom as he gradually took on more of the role himself.

Taking Care Of or Taking Over?

A significant theme to emerge in the interviews was the tension experienced by individual family members as they struggled to find the right balance between supporting Rose by taking over activities and decision-making that were difficult for her versus supporting her to maintain her independence, even at the risk of a failure that might cause her distress. This tension, debated in health care ethics as the conflict between beneficent care and respect for autonomy, is necessarily an ongoing negotiation in the day-to-day world of caregiving, and it was represented conversationally in the Tanaka family by conflicts and mitigations in how participants, including Rose, positioned her in their talk. These conflicts and mitigations occurred sometimes between participants and at other times within the same participant's account.

The first example of these tensions to consider occurred in a conversation among Rose, Tom, and their two daughters at the end of a family meal together. Tom had introduced the topic of a future trip for himself and Rose, with the possibility of having Maria accompany them. He, Linda, and Maria were discussing the alternative advantages of going to Hawaii or Thailand; Rose did not participate until invited to do so (see Appendix E, Transcript 2 for complete excerpt):

Excerpt 5.20

69. T: the *first..*thing is...I've *got to...find out about the *air/
 70. whether...uh...whether I can arrange-
 71. *maybe I'll look *after that//
 72. L: =={[h] *you liked Thailand, didn't you Rose?}
 73. T: *yeah/ *I'll see if I can-
 74. R: {[h] yeah::_ *I liked it_
 75. T: do *you know how to turn that *unit off?
 76. {[pp] 'cause *I think we're just about *done//}

[A few turns follow here concerning turning off the tape, and Linda's preparing to leave]

85. T: *that's in the - *that's in the *works,...um::_
 86. M: *which - which one did you want to - did *you want to -
 87. if *you had a *choice between Ha*waii and *Thailand/
 88.. *which one would you wanna *go to//
 89. <3>
 90. R: {[h] um::_...I *like *Thailand,..}
 91. M: mm*hm, ..=do you wanna go *back?=
 92. R: =um::_.. because =
 93. there was *kind of a lot of *villages, and- and things,
 94. and *people were more... uh.. *easy to *talk to,
 95. M: mm*hm,
 96. T: {[~]**talk to?}
 97. M: {[p] yeah/}
 98. L: well *they spoke *English,
 99. T: =*hmm?=
 100. M: =yeah/=
 101. did you- would you prefer *Thailand?...or..or..Ha*waii//
 102. L: well *they can do *both, *she can do *both,

[discussion moves away from Rose's preferences to family logistics, with no further participation from Rose]

[C/RTLM.8.67: 1:04:53-1:05:53]

Linda, in line 72, prompted Rose's participation by establishing both that she had been to Thailand and that she had liked it, so might be expected to have an opinion about going there again. Rose, while acknowledging her past experience, did not take advantage of this opportunity until Maria explicitly asked about her preference. In doing so, she backtracked to orient her mother to the discussion (line 87). The following stretch of talk

was characterized by a change of pace that made it stand out from the surrounding few minutes of discussion. Rose's answer followed a significant pause, during which no one else spoke, with the exception of Maria's overlapped prompt (line 91). Nor was there any sound of background activity; everyone present waited for Rose's response, creating a conversational space to facilitate her participation in the discussion. Yet, even given those prompts, Rose's comments about Thailand could not necessarily be taken as preference for travel there. Tom's exaggerated repetition in line 96 of Rose's words could be interpreted as dismissive, potentially undermining Rose's credibility in knowing what she preferred. Her daughters, however, interjected with support for her comment, even though just a few minutes earlier, Linda herself had suggested that Hawaii might be more relaxing because everyone spoke English (see Appendix E, Transcript 2 line 41) while Maria had commented on additional stress in travel to Thailand associated with not knowing the language (see Appendix E, Transcript 2, line 59). Indeed, Rose may have been incorporating her daughters' earlier comments, albeit incorrectly, to construct her response, possibly contributing to Tom's challenge of her ability to make an informed decision. Nevertheless, her daughters' defense of her claim, coupled with Maria's repeated question in line 101, demonstrate their willingness to maintain at least the appearance of her participation in decision-making.

Differences in positioning did not necessarily result in overt challenges. The following excerpt took place during the lunchtime conversation with Rose, Linda, and Maria:

Excerpt 5.21

1. L: so have *you been in the *water Rose?
2. R: {[h] yeah_.. *I've um-} was it *yesterday? or the day be*fore/

3. L: you went for a *swim?
4. R: mm*hm,
5. L: oh *good/
6. R: {[l] *Alison says/}
7. L: ==but *only do that when someone's a*round though/
8. eh?
9. R: *oh yeah/
10. L: yeah/
11. R: =no *I won't *go in alone/ =
12. L: ='cause *even uh..*adults get =cramps/
13. R: =*oh yeah/ =
14. L: =it's *not just -= ..it's *anybody can get a cramp/
15. {[p] in their..in*testine//}
16. R: 'cause *Alison says to me/ ..when I went *in? [clears throat]
17. *you know/ kinda- I *didn't really *dive/ I *just went - ..from the *skip/
18. and she comes *running on the *side/
19. and she says/..{[breathy] *oh::/ grandma *Rose/}
20. {[dc] *you are *so {[hehheh**good/}}}
21. M:[heh-heh] she's *cute/
22. R: she says/ *where did you **learn::/ she says/ *you better *teach me/
23. she says//
24. M:[heh-heh]/
25. <3> o*kay? well I guess I should get the bill?

[C/RLM.1.32: 35:05 – 35:54]

In this excerpt, Linda's admonishment in line 7 positioned Rose as dependent, requiring advice because she was unable to adequately assess risk for herself. Even though Rose immediately agreed with the advice, Linda went on to reinforce and simultaneously mitigate this positioning. Her comment in line 12 about "even adults" implied that her concern was not because of any lack of confidence in Rose's abilities, but at the same time her need to restate it suggested a lack of confidence in Rose's ability to remember it. This dual positioning is carried into the next line, where her revision in line 14 leaves open to speculation what she rejected in favour of "it's *anybody". Rose, in agreeing with Linda's advice in line 11, both acknowledged Linda's concern for her and also established herself as aware of the risk of swimming alone. This self-positioning may also account for the distinction she made in line 17, claiming that she "didn't really dive"

but “just” went in from the skip. In view of her subsequent positioning of herself as a grandmother with accomplishments admired by her grand-daughter, her modified account of going into the water may have been in deference to her daughter’s concern for her, signaling her awareness of the risks associated with diving. These alternative positionings were allowed to stand without direct challenge. However, the neutrality of Maria’s contribution in line 21, as well as her topic change in line 24, suggests that her acceptance of Rose’s self-positioning did not necessarily constitute agreement with it.

In another excerpt from Rose’s lunchtime conversation with her daughters, the question of autonomy was addressed differentially, depending on whether the context was within or outside the family.

Excerpt 5.22

1. R: I would *pay for it/ but I - I *didn’t bring my *purse today//
2. M: {[h] oh/ it’s=*okay/} =
3. L: = no no =no/
4. M: ==no it’s *okay/
5. L: {[h] you know *what? it’s *probably better} not to *bring it,
6. if you’re *just coming to the *office?
7. M: ==yeah/
8. L: ‘cause you *don’t **need it/..right?
9. M: ==yeah/
10. L: ==and you’re *just gonna
11. ...for*get it or whatever//
12. R: yeah/
13. L: I mean *when you go out/ it’s *different// but_
14. R: this is *yours/ is it?
15. L: yeah//

[C/RLM/1.33: 35:55 - 36:12]

Rose’s opening offer in line 1 positioned her as independent, willing to take her daughters out for lunch but unable, on this occasion, to do so. Her daughters’ rapid, overlapped reassurances both served to mitigate any threats to face arising from not

allowing her to pay. First, Maria's comment in line 2 acknowledged her offer but rejected the need for it; the discourse marker "oh" can be used to acknowledge information (either new or familiar) and can also simultaneously mark a subjective change in orientation to that information (Schiffrin, 1987). The pitch change in Linda's next comment marked a shift in topic away from who would pay on this occasion to Rose's needing a purse at all. Her suggestion in line 8 that Rose did not need it implied rejection of her offer to pay for lunch with her daughters on not just this but also on future occasions, subtly positioning her as dependent. Her motives, however, were arguably to spare Rose any unnecessary consequences of the frustration of forgetting her purse (line 11), drawing a distinction between what would be acceptable within the family, where there was no need for her to pay, and what would be expected of her in going out. This distinction emphasized family solidarity and caring over individual autonomy and Linda's suggestion, supported by Maria, passed unchallenged.

In some instances, in contrast to the foregoing examples, Rose did not allow others' positioning of her to go unchallenged. During a visit with her mother, Maria offered to do Rose's hair for her, leading to this exchange:

Excerpt 5.23

1. M: do you *know what I should *do ma/
2. {[p] *why don't we.. *quickly do your *hair/
3. ..be*fore..*everybody comes *home/ ..it'll be *good/}
4. R: why// do you *think it looks *awful?
5. =(do you think it *needs something?)=
6. M:={[f] *no/ it looks *fine/} =
7. it looks *good/ but *maybe I'll just do a...just to do a quick *wash/
8. and then -
9. R: {[p] mm*hm,}
10. M: {[l] you can *style it//}==it looks *nice/ I *like it without the curls//
11. R: mm*hm,
12. M: {[p] it looks *nice//}

13. R: yeah/ this is e*nough?
 14. M: yeah/
 15. R: =*wave in it//=
 16. M: =I'll uh- I'll- =
 17. R: yeah//
 18. M: *I got wave *too//
 19. R: =yeah/ (xxx that/=
 20. M: =yeah/ *I'll just = go get a *towel and I'll be *right back//
- [C/RM. 2.12 14:20-14:47]

Rose's response to this gesture of care was to treat it as a threat to face, interpreting it as criticism of what she had done herself, and calling her autonomy into question. Maria accordingly devoted the next several turns in mitigating the implications of her initial offer, minimizing her own proposed role to "just...a quick wash", suggesting that Rose should style her own hair, and thereby emphasizing her acknowledgement of Rose's independence. Maria's following compliments moved the conversation even further from the offending offer, ending with an affiliative comparison to her own hair in line 18 and, ultimately, to agreement.

It is clear from the interview findings that family members can and do reflect consciously on understandings and expectations of each others' roles, creating for themselves internalized representations of these roles that can be the objects of further reflection. It is equally clear from the conversational excerpts that in everyday life these roles are constructed and negotiated conversationally through joint interaction. It is not the contention here, however, that these negotiated constructions are deliberately motivated by individuals' conscious understandings but, rather, that these two kinds of representations, that is, internal and interactive, are intimately and inextricably interwoven. From this perspective, consistent with symbolic interactionism, conversation is fundamental to intersubjectivity, allowing us to hold a shared view of our everyday

world; it is the basis of social life. As a process, conversation in the context of Alzheimer's disease has so far offered a lens to focus on constructions of disease and changes in family life, but it also can be itself the object of inquiry and of conscious reflection. In the next section, I explore how family members talked about and accommodated to changes in conversation.

Alzheimer's and Conversation

Interview Representations

In talking about changes in conversation associated with Alzheimer's, Rose's family members all described similar patterns in her contributions. All talked about her telling the same stories and asking the same questions repeatedly. All described her as participating much less, if at all, in conversations with larger groups, although they also described her as enjoying talking with others in a variety of settings. Tom, in talking about taking Rose with him to different social events, commented that "she does..enjoy...chatting with people//" [IT: 847]. Linda and Maria too described Rose's social conversations with people around Linda's office, commenting that "she talks to them more/ on a social level? than to us/ I think//" [IL: 866-870]. However, in contrast to these signs of preserved social skills, Linda also described her as making negative comments to or about others that she would not have made before, in addition to chatting socially with people when it was not appropriate for her to do so. Family members too noticed changes in topics of conversation, with ever fewer dominating: stories of the past, her grandchildren, her daughters' cats. Rose herself showed some awareness of the effect on others of her conversation, though there is no evidence that she linked it to

Alzheimer's. In an unrecorded conversation with me, when I was reminding her about the goals and methods of the study, she asked me to let her know if she was not "talking properly", because sometimes she said things that were not quite right. Similarly during our interview, in describing speaking with other wives when she and Tom visited his friends, she said: "when I start talking too much about my children/ you know? she'll think/ oh my {[heh-heh] **god/ you know/}" [IR: 997-998].

While family members were consistent in their accounts of changes in Rose's conversation, their responses to those changes were remarkably individual, despite points of similarity, particularly along gendered lines. This individuality stands in strong contrast to the dominance of the family voice that emerged in the context of all other topics. The following section describes the response of each individual family member to changes in conversation.

Tom: "There's No Point"

For Tom, the first comment about changes in his conversations with Rose was that they had become "very very limited" [IT: 718]. He attributed her enjoyment of social outings in part to their own current lack of conversation, saying "it's partly because..I don't.. we don't talk that much/ {[heh-heh-heh] *no:/ we *don't/} {[ac] *you know/ sitting down and *talk/}" [IT: 726-728]. He described himself as "probably one to blame for that/ because uh...[omitted] I would "just as soon/..uh.. sit at my computer/" [IT: 773-775]. At the same time, he pointed out that "if you've been married/ for a long long time/.. {[heh-heh-heh] you don't spend/} a lot of time talking// you know/ body language quite often/ ...suffices/ you know?" [IT: 786-789]. However, when asked if he thought that their long marriage, more than Alzheimer's, contributed to their lack of

conversation, he commented: “[dc] more so..because of Alzheimer’s/ I think//} because really there’s no point in..my/ uh..saying what – or discussing what we should do/ I’ve got everything planned out for her/” [IT: 796-799]. While he attributed this in part to Rose’s memory problems, he also expressed some uncertainty about whether she was actually listening to him in conversation: “maybe she listens/ to conversations with me/ I don’t know//” [IT: 733]. From this and similar comments, several of which included the phrase “there’s no point”, it appeared that for Tom, who clearly enjoys traveling and looks forward to social events, a significant loss in conversation was the loss of sharing the planning for upcoming events. He contrasted the conversations that he could still have with Rose: “so all I can do is talk about/ ..a long time ago/ period// you know? ..and um..that’s okay on a casual basis/ for acquaintances/” [IT: 741-745] with what was now, from his perspective, lacking: “there’s hardly any..*real dis*cussion/” [IT: 781]. For Tom, Rose’s conversational needs were best met in casual social conversations with others.

The theme of “no point” was repeated in Tom’s comments about Rose reading the newspaper. He described her as an avid reader, going through the newspaper slowly, reading everything, “every single item” [IT: 764]. Tom described this activity in terms suggesting futility: “I don’t know why she does that/ / ‘cause she can’t retain anything” [IT: 764-765]. For him, reading, like conversation, required a purpose beyond the act itself to be meaningful.

Colin: “Filling Up The Conversation Time”

Colin, like his father, described a decline in conversations with his mother, and, like his father, acknowledged his part in that: “I would have to say/ I don’t..speak to her

as much" [IC: 421]. He too alluded to her tendency to repeat the same stories but for him, unlike his father, these became the focus of their current conversations:

"I guess we..probably talk..maybe about the same,
but it's [omitted]
my response is..instead of..asking more questions about a story/
since I {[heh-heh] already know the ending/}
I may just nod my head or..or..um..you know/
say yes or no, or say / is that so..type of thing/"

[IC: 425-435]

On further reflection, Colin suggested that, overall, "there's probably a lot less talking altogether/" [IC: 444], again alluding to his own behaviour: "it's sort of sad to say/ but I..almost feel that if I..tell her something/ she's not going to remember the story/ so it's..almost a waste of breath/ other than filling up..the conversation time/" [IC: 447-449]. His conclusions were undoubtedly supported by his observations of his daughter's conversations with his mother: "my daughter does most of the talking/..my mom's..a lot of her answers,..aren't really answers/ they're just..nods of the head/ acknowledgement that..she's listened to the story/" [IC: 522-527]. Colin, like his father, saw information that was not retained as information that was wasted; unlike his father, he appeared to be more willing to take part in conversations about the past, if only to acknowledge through backchannelling his role as listener.

Linda: "We Don't Have Conversations Anymore"

In Linda's discussion of changes in conversation with her mother, she focused more on the difference in quality of talk than on quantity. In doing so, she differentiated between conversation and other kinds of talk, saying: "I don't think we have conversations anymore// they're..just comments?" [ILL: 583]. Linda gave several examples of ritual exchanges: "she remarks on the price of gas, every morning when I

pick her up, you know/ it's gone down, or up?" [IL: 584]. She went on to explain how at first she tried to extend those exchanges into conversation by asking questions that linked them to Rose's past, but tired eventually of hearing the same stories in reply. Another ritual exchange was Rose's daily question about Linda's cats. Like Colin, Linda believed that her mother, even when asking for information, would not remember it, commenting: "when I have to say one day, that the cats have passed away?...she'll still ask me though" [IL: 605-606].

In addition to exchanges routinely initiated by Rose, Linda described exchanges that she herself routinely initiated. These included questions to which Linda knew at least part of the answer, as in for example, "so what did you do yesterday" [IL: 594], in which she could use her foreknowledge to prompt Rose if needed. But these, too, for Linda did not constitute conversation: "they're just reports" [IL: 599].

For Linda, there is an explicit connection between conversation and relationship. In reflecting on her and Rose's communications (a word that she used instead of conversation), she commented:

"it's very one-sided? and you know/
relationship is really two-sided? you've gotta give, and take?
that's..so the part that she asks me? it's just my cats//"

[IL: 1055-1062]

Her comments draw attention to the one-sidedness inherent too in Colin's descriptions of Rose's conversations but, unlike him, Linda tried consciously to identify ways to keep interactions going: "I remember thinking that- um::/ <3> I have to ask her about something/ the next time I pick her up/" [IL: 886]. At the same time, she was aware of making "small talk" [IL: 894], something which she described as hard to do with Rose, adding that she was similar to her father in that regard. Linda, together with the rest of

her family, avoided telling Rose in advance about significant events, not because Rose forgot them, but because of the consequences of her partial forgetting, namely, her repeated questions and anxiety about them; yet this, too, contributed to one-sidedness in their conversations.

Maria: "You Find Ways"

Maria identified herself as the one among her siblings "who actually **talks to her one on *one" [IM: 456]. Her emphasis on "talks" gave it a special status in her account, which became evident in her description of that talk. In discussing changes in her mother's conversation, Maria's first comment drew attention to changes in her own: "you do *change//..you find ways:://" [IM: 426-427]. These included not only specific strategies to mitigate the effects of behaviours associated with Alzheimer disease, but also a change in her expectations and goals of conversations with Rose. For Maria, the act of talking with her mother appeared to be a meaningful end in itself, with content a secondary consideration. She alluded to "safe stuff" [IM: 459] including grandchildren, the past, her mother's repeated questions about her business or about her cat; both could draw on these topics to maintain conversation. Maria clearly recognized that while these offered a way of sustaining conversation with her mother, they sometimes led to more:

but as time goes on/ and we're just sitting there/
she will have older memories that she knows/ and that..she feels confident about/
and sometimes there'll be some new stories/ that I'm..totally excited about/
[IM: 461-466]

At the same time, she acknowledged her own frustration:

other times it's a little – it's tough//
um..I think sometimes she can see:: sometimes/ the frustration?
in other people/ and even myself/
that we can't have the same conversation/ that we used to// [IM: 466-469]

In addition to encouraging conversation with her mother by spending time with her alone, Maria also engaged her in groups where, according to all family members, she tended to withdraw from the conversation. She did this by going “one on one with her” [IM: 483], an act that I observed in my first meeting with the whole family. During a discussion with them following my description of the research project, Maria engaged in a sidebar conversation with Rose, checking to ensure that she understood the discussion and encouraging her to express her own opinion about taking part in it

Rose: “I Don’t Even Think Of It”

When I asked Rose about whether she had noticed any changes in her conversations with people that she associated with having Alzheimer’s, she answered: “I don’t realize it// I don’t even think of it//” [IR: 1047-1049], going on to explain that she feels “like anybody else” [IR: 1051]. For Rose, an important consideration was her conversation partner: “..but as long as I don’t annoy anybody, uh..and I come out with something foolish, well,..that’s me//” [IR: 1056-1058].

Integrating Accounts of Conversation

Despite the individuality of each of Rose’s family members’ accounts of conversations with her, there are comments that resonate across their perspectives. The one-sidedness of conversation, described explicitly in Linda’s account, was a significant theme in all interviews, though to a lesser extent in Maria’s. However, family members differed in the ways in which they interpreted and accommodated to this one-sidedness. Tom and Colin focused on their own gradual withdrawal from telling Rose anything because she would not remember anyway, with both also expressing some doubt as to

whether she actually listened. Their comments suggest that for them the informational exchange in conversation, rather than the act of conversation itself, was most important.⁸ Yet, in his own way, each man also acknowledged relational goals in recognizing the importance of supporting Rose to maintain conversations in whatever ways she could, with Tom facilitating opportunities for her to chat with others and Colin accepting a role as listener, albeit a passive one, for her repetitions of old stories. In contrast, Linda and Maria spoke of conversation in terms of relationship, emphasizing the importance of the act of conversation itself. Both daughters worked to maintain their own conversations with Rose, although they differed in how they did this. While Linda looked for ways to restore more "two-sidedness" to conversations, Maria, like Colin, accepted her mother's hold on the conversational floor; indeed, she sometimes welcomed it as a way to facilitate talk with Rose. In contrast to Colin, Maria's description of her own participation implied a more active role leading, on occasion, to learning something new. For her, information was not the goal of conversation but, rather, an unexpected by-product.

These accounts of conversation point to the interdependence of conversation and relationship. The theme of one-sidedness emerges, not just as a loss of content and balance in talk itself, but also as a failure to sustain shared goals, shared interests, and mutual concern. The unique status of each family member's relationship with Rose is emphasized in the individuality of each account of their conversations together, but a unifying theme is that the increasing one-sidedness of those conversations posed a threat to those long-standing, special relationships.

⁸ This emphasis on informational over relational goals in conversation has been described as a feature of male versus female talk (Kendall & Tannen, 2001). However, because it was not the most salient aspect of conversational goals in either family, specific analysis of gendered aspects of talk has not been undertaken.

Conversational Representations

Family members' accounts of changes in conversation invite an exploration of one-sidedness, in terms both of how it emerges in conversation and of how family members work to restore balance. Yet one-sidedness as a phenomenon is difficult to exemplify. The conventions of conversational turn-taking, identified by Sacks, Schegloff, and Jefferson (1974), allow for the possibility of one participant taking control of the floor at any given time, but characterize it nonetheless as a collaborative achievement, with the other participants marking their roles as willing listeners through backchannelling (e.g., "mmhm" used to encourage a speaker to continue) or completions that serve both to convey interest and to move the discourse forward. Attention to these moves at a local level can reveal how the participants negotiate control of the conversational floor, but it is by considering conversations at a global level that we appreciate the collaboration among participants as they share and exchange the roles of speaker and listener to achieve mutual conversational goals. One-sidedness, then, as a pervasive feature marking changes in conversational relationships, necessitates consideration of both quality *and* quantity of talk.

In the Tanaka family conversations, there were numerous instances of "two-sided" conversations with Rose, in which she participated collaboratively as both speaker and listener. These warrant attention, not to refute the characterization of one-sidedness, but rather to highlight it. Though there were in absolute terms many such instances, they were nonetheless relatively infrequent in the context of nearly five hours of recorded conversations with Rose present. It is in contrast to these that the quality of one-sidedness becomes apparent, in some cases with Rose as dominating speaker, and in

others with her as absent listener. Analysis of these different interactions, in addition to identifying features that mark them as such, can inform our understanding of strategies used by individual family members, including Rose, to sustain interaction.

Two-sided Small Talk: Multi-party Conversation with a Stranger

Several family members commented on Rose's enjoyment of and ability to participate in small talk with people outside her immediate family; Linda suggested that she seemed to engage in those even more than in conversations with her own family. In the corpus of data for this study, there was only one such conversation, recorded when I met with Tom and Rose for morning coffee. At that point, we had met several times; I had interviewed each of them in their home and we had gone to a restaurant for lunch together (not recorded), so for both Rose and Tom I was a relatively recent acquaintance. During that visit, Rose assumed the role of co-host with Tom, leading me out to the deck to look at her flowers and showing me pictures of her grandchildren while Tom made the coffee. Throughout the hour-long visit, the distribution of talk varied, but analysis of the conversation suggests that Rose was always involved, sometimes as speaker and sometimes as active listener, even during stretches of talk in which Tom dominated as speaker. For example, with the exception of a relatively short digression, one topic lasted for nearly fifteen minutes, as Tom described his ballroom dancing with occasional interjections and questions, primarily from me. While Rose's active participation was relatively limited during that time, she nonetheless showed evidence of listening, as in these examples:

Excerpt 5.24

1. B: was the *ballroom *dancing a/...*I don't know/
2. was it a *certain *point in the *lesson? or was it *just =a:- =
3. T: =well/=
4. it's a- {clears throat} it's *run by a *very good..uh..um..*couple,
5. a..the *main *guy- the *person is..a *Chinese fellow/ uh..#name#,
6. B: mm*hm,
7. T: and uh..his *wife/..*helps him but/
8. *he..*he's been voted the *best.. in*structor/ I *think in B*C/
9. or at *least in BC/ it *might have been across *Canada//
10. ..*three years *running,
11. B: mm*hm,
12. T: [clears throat]
13. B: *hmm/
14. R: =*Chinese are good =*dancers/
15. T: =and *he has - = ==*he has..over a *hundred *students//

[C/RTB.5.5. 9:04-9:48]

[The conversation between us continued for approximately four and a half minutes, with only the occasional backchannel or chuckle from R, and then T explained how his group had arranged for a place to practice between lessons]:

16. T: we *rent a *hall/..for a *very *nominal..{[p] fee},
17. ..uh..in Van*couver/
18. B: mm*hm,
19. T: *we just pay..what a*mounts to about a *dollar per *person per *night/
20. B: *oh/ *great/
21. T: and we *practice/..what we uh.. *learn/..at the Grand *Ballroom/
22. B: mm*hm/..oh *I see/
23. T: =yeah/=
24. R: =oh = *that's good then/ so.. you're a*way from the thing,
25. T: =so=
26. R: =and= you *learn more//
27. T: *this is very *nice/ *Barbara,
28. B: *thank you//
29. R: yeah/ *very nice/ *very good//

[C/RTB.5.8: 14:18-14:48]

[After a minute or so during which R and I shared the floor on the topic of food and cooking, I moved the topic back to dancing]:

30. B: so do *you ever do any ballroom *dancing Rose?
31. R: {[I] *no/ *not much}, ..he's *finally get *better/
32. so (I'd be able) to *follow him/
33. {[heh-heh] but I *can't know what he's *doing//}
34. =[heh-heh-heh]=

35. T: =it's a- = *I never used to *care too much/ about *dancing/
[C/RTB.5.9: 16:07 16:22]

[After five more minutes, during which Tom talked about how he came to taking dancing lessons, the conversation moved back to his lessons at the Grand Ballroom, during which he also described himself as not being a very good dancer, and leading to this exchange]:

36. T: *men are..in short sup*ply,
37. B: =mm*hm, =
38. T: =you *know?=
39. so *hey/
40. *I don't have a.. *problem if a woman really ap*preciates somebody/
41. who at *least knows which is the *left foot/
42. and which is the *right =foot,=
43. B: =mm*hm/= =*yeah/ =
44. T: =[heh-heh]=
45. R: =[heh-heh]=
46. B: *yeah/..I'd ima*gine you're pretty *popular at *dances//
47. T: {[p] so/} ..*well/
48. R: ==well you *know-
49. T: ==it's *not-
50. R: *Chinese people are *very very good in *dancing//
51. T: {[p] yeah/ *they seem =to- =}
52. R: =*gee/= are they *ever =good//=
53. T: =ap* =preciate that//
54. well/..*this..Grand *Ballroom/...because..the in*structor is Chi*nese/
55. B: mm*hm,
56. T: *I would say about..*ninety..five per*cent/ are Chinese *students//
57. B: *hmm//
58. T: {[pp] yeah/}
59. B: {[ppp] hmm/}
60. R: {[p,l] they're *very good/ when it comes to *dancing//}
61. <7>

[C/RTB.5.13.21:42-22:30]

These examples show that, despite Rose's relatively minor participation, she was listening throughout. Her contribution in line 14 built on Tom's comment in line 5. Her repetition of the point in line 50 was relevant to both the return to the sub-topic of the Grand Ballroom, where the instructor is Chinese, and to the new sub-topic of Tom's skill; that it was accepted as relevant is indicated by Tom's extension of it in the next few lines.

It also served to bring about topic closure, marked by the drop in volume, pitch, and content of the next few lines, and prolonged silence in line 61, so that Rose's reiteration in line 60 appears, not as an unintentional repetition, but as a topic closure move.

Further evidence of Rose's listening is seen in her comment in line 24, which followed several minutes without any audible contribution from her. It indicated her attention to the talk and was one of relatively few instances in the overall data set in which Rose self-selected as speaker in a multi-party conversation. Her comments in lines 31 and 32 offered an account of her willingness to accept the role of listener: dancing was one of Tom's activities, which she supported but did not share. That it was not a shared activity was explicitly acknowledged here; that she supported it was implicitly acknowledged throughout the conversation in which her infrequent, but relevant, contributions marked her role as an active listener as she allowed him to hold the conversational floor.

At other points in the conversation, Rose participated more actively in the interchange of speaker/listener roles, as in this excerpt, after I introduced the topic of problematic swans in a local park (see Appendix E, Transcript 3):

Excerpt 5.25

1. B: so - so the *parks board had to *build a [heh-heh]
2. had to *build a *fence around the *=swans'*nest? =
3. R: ={[~] *oh::: =
4. T: =heh-heh =
5. B: so that *people would be pro*tected from the *=swans/ =
6. T: ={[heh] the *swans/}=
7. B: *not =the other =way *=round/ =
8. T: =not- *yeah/=
9. R: =way *round/= *yeah/
10. B: I *don't think they were worried about *people -
11. ..I *think they were just worried about the *swans at*tacking=people/ =
12. R: =at*tacking/=

13. =yes/ =
14. B: =because= if they walk =*into *range/ you *know? =
15. R: = oh:: *yeah/ oh **sure::// =
16. B: =*I wa=-
17. R: =(to be)= because – with their *big =*heads,=
18. B: =*oh/ =
19. R: and their big *things,
20. B: =they're =
21. R: =they'd = be *going like *this/ you know?
22. B: they're so *ugly when they're *doing that/ ..don't you *think?
23. R: yeah/
24. B: when they've got their *heads out,
25. =and they're- =they're.. at*tacking, =and- =
26. R: =mm*hm, = =going =*after something/
27. B: *yeah/
28. <2>
29. I was *thinking/..you *wonder how they managed to get the *nest-
30. the **fence around/
31. without the *civic workers getting.. attacked by swans as *well/
32. R: {[p] *oh/..oh *I see, {[pp] yeah/}
33. B: {[p] so_}
34. R: ...{[h] *we had about }..four or six little baby *ducks/
35. and one *mother one/
36. T: yeah/
37. R: *swimming in our *pool//
38. T: =[heh-heh-heh]=
39. B: =*oh:/ =
40. R: in the *morning I look *out/
41. {[ac] I *always *do that first thing in the *morning/
42. to *make sure that there's nothing in there/ =*dead/
43. = or a *bird or something/}
44. B: =yeah, = == yeah?
45. R: and *here's the mother *duck, ..and *then uh..uh
46. ...she-.. she would *go around like *this on the *edge/
47. B: mm*hm,
48. R: so that-..the- the *little ducks-
49. {[h] the *little ducks} were *just like *this/ =you *know? =
50. B: =[h] *oh::/} =
51. R: so that *they were trying to *keep up with the *mother duck/
52. T: ==*these ducks were-...*obviously unable to *fly yet/
53. B: uh*huh?
- [remainder omitted, in which T takes over more active role but R contributed through backchanneling]

[C/RTB.5.26.40:48-42:00]

Rose's and, to a lesser extent, Tom's numerous overlapping exclamations, laughter, and repetition of my phrase endings mark their collaborative support of my story-telling (e.g., lines 9 and 12). Rose's comments in lines 17, 19, and 21, as well as her phrase completion in line 26 contributed further to the story without taking over the floor. This type of overlapping has been interpreted, particularly in women's talk, as collaborative rather than interruptive, marking an affiliative style of discourse (James & Clarke, 1993). Rose's comment in line 32, however, suggests that although she recognized a place for a turn at that point, she had not really followed the previous comment; her remark functioned less as a response than as a topic closure move. Its lack of congruity with the preceding turn, in contrast to the foregoing collaborative discussion, suggests a lapse in either attention or comprehension, and my next comment supported her move to end the topic. In the next line (34), Rose took control of the floor herself by shifting the topic to the related subject of ducks, maintaining control for the next several turns but ultimately ceding the floor to Tom as he took over to explain how he got the ducks out. After a couple of minutes during which she participated once again in the role of listener, she regained control of the floor by shifting the topic to raccoons:

Excerpt 5.26

1. T: *they were *there for maybe an *hour?
2. B: *okay/
3. T: yeah//
4. B: ..and you *never saw them a*gain/
5. R: no/ so they just *happened to walk through.. the *road or something,
6. or um..some *dogs, you *know?
7. B: right/=right// =
8. R: =and uh-=
9. B: *I thought maybe they'd actually been *living in your *yard/
10. the whole *time/
11. and then when it was *time to have the *=ducks - =
12. R: =(ducklings)=

13. B: *okay/ so *now I have a place to teach my *=babies= to *=swim,=
 14. R: = (xx) = = yeah/ =
 15. B: *you know/ but-
 16. T: it *=must= have been=-
 17. R: =we = had rac=*coons/ =
 18. T: =it *must = have been a *nest somewhere/
 19. =*very close *=somewhere/
 20. R: =it *could be/=
 21. B: yeah/
 22. T: because we never *did see/ the *mother duck/
 23. R: *no/...but I *looked under that *tree we had/*what was that *tree we had//
 24. T: ...oh/ *you're talking about the rac*coons/ *yeah//
 25. R: yeah/ *I happened to *look/ under*neath/..that uh..*tree and the *branch/
 26. and then *I *see about *half a dozen **eyes::/ **staring at me/
 27. B: *hmm/
 28. R: *that was because/..it was *=dark/=
 29. T: =ki- = *kiwi plant//
 30. R: yeah/ *kiwi plant//..*anyh-..**oh::/ they were *looking at me/
 [C/RTB.5.27.44:32-45:26]

Tom supported her resumption of floor control in line 24, contextualizing her comments and in line 29, adding supplementing information but without attempting to regain control of the floor. These actions exemplify the joint storytelling behaviours that are described as characteristic of spousal dyads (Kemper, Lyons, & Anagnapoulous, 1995).

Taken together, the foregoing excerpts illustrate that, in the context of small talk with a relatively unfamiliar guest, Rose was skilled in assuming the roles of both speaker and listener, participating with Tom in an interchange of these roles as each foregrounded their own stories, and contributing to the overall flow of conversation through a variety of topical moves. Although she occasionally repeated herself, these repetitions facilitated her participation in the conversation. Similarly, the formulaic "oh I see", although a non-sequitur in excerpt 5.25, served to close my topic and facilitate the introduction of her own. In this light, behaviours that can be otherwise attributed to the symptomatology of AD can be interpreted as facilitative accommodations serving to sustain interaction.

Rose's strategies were successful in the context of this multi-party small talk, which was further supported by the nature of the interaction itself. My visit followed a clearly familiar social script of having coffee with a casual acquaintance, a script in which Rose presented herself as co-host with Tom. In accordance with the social obligations of that role, she participated actively in the conversation, introducing her own topics and contributing to those of others. However, this type of script places few constraints on topic selection, especially in this circumstance where, from the Tanakas' point of view, there was no goal beyond the interaction itself. In family life, however, conversational goals can be both more specific and more complex, necessitating potentially different strategies for Rose to maintain conversations.

A Shared World: Multi-party Family Conversations

Dinner-table conversations are well recognized as a special part of family life, contributing to solidarity of the family as its members share their experiences and concern for each other, and to the ongoing construction of family identity through members' talk of past, present, and future. Rose's family members all commented during their interviews on her gradually diminishing participation in multiparty family conversations, with some also identifying strategies they used to include her. The video recorded dinnertime conversation including Rose, Tom, Maria, and Linda provided an opportunity to explore Rose's participation in family talk.

Throughout the dinner, Rose participated actively in its organization, pouring tea for others, clearing up (see Excerpt 5.9), and serving dessert (see Excerpt 5.6), so that there were many instances in which she was involved in sidebar talk focused on the meal itself. However, the talk was more often focused on topics unrelated to the meal: events

in the lives of other relatives, their own recent activities, plans for upcoming events, stories about past events. Analysis of that talk showed that Rose was often not involved in it, with little backchannelling and few on-topic contributions that were not responses to her daughters' direct questions (as in, for example, Excerpt 5.20, lines 2, 9, and 22).. One such contribution was seen in the conversation about Christmas dinner (see Appendix E, Transcript 1, line 35) which, as noted earlier, seemed to be directed to Rose, thereby implicitly soliciting her participation. In the hour-long conversation, there was only one instance in which she self-selected as next speaker in talk that had been moving rapidly among the other three, overlapping Tom, who yielded the floor to her. The topic, introduced by Linda, was a recent photo show that Tom and Rose had attended with a friend (for complete transcript, see Appendix E, Transcript 4):

Excerpt 5.27

1. L: {[h] did you *go to that}..um/...*photo,...um...thing? with um/...*Bob?
2. ==that *photo..*gallery?
3. T: hmm? =oh *yeah/{[p]..yeah yeah//}=
4. L: =or..that *show? =
5. T: yeah/ yeah/
6. L: what was it *like/
7. T: it was *good/
8. ex*cept that this uh..=*lady/ =
9. M: =it was = the in*termment uh.. *photos/= ma,=
10. T: =*she=
11. just *talked and *talked// *you know? when *one gives a *talk/
12. *maybe *twenty minutes *you know/ at*tention span/
13. T: =just- =
14. M: =yeah/ =
15. L: =mm*hm/= I *know/
16. T: but *these people who are -
17. M: {[p] *they don't know/}
18. T: *no no/ but they- *they should -
19. they- they- they - *they get up in *front of people, uh *talk,
20. and *this lady was-
21. I *think she's probably {[dc] as*sistant prof or something} at UB*C/
22. M: =mm*hm,=

23. T: =..or - I'm= sorry/ Simon *Fraser now//..*she should know *better,
 24. *she -.. went for about-.. over an *hour//
 25. L: {[dc] *holy =**smokes//=
 26. T: =yeah// =
 27. L: *I didn't *know it was a - um::_
 28. M: ==she probably thought it was like a *class/ =you =*know?
 29. T: =hmm?=
 30. they're =*used= to doing classes/ =for =about =*fifty= *minutes//
 31. T: =mm/ = =yeah/= =well=-
 32. =people- they- =
 33. R: =*I felt ...sorry= for the /haku*jin/ people that came and *sat there/
 34. because-
 35. T: ==*well/ so-
 36. L: ==*why//
 37. R: but- *you know / we *knew what she was *talking= about, =
 38. M: =yeah/ =
 39. R: =like Lemon *Creek and all *this=-
 40. T: =no *no/ the *fact is/ = *people's= at*tention span/
 41. M: =hmm/ =
 42. T: *you know/
 43. L: ==is *basically= as long as your= your- your- butt can.. =*take//=
 44. T: =goes a*way// = =yeah// =
 45. L: {[ac] did *you en*joy it Rose?}
 46. R: {[h] um..oh/ in {[~]*ways},
 47. because they *had a lot of *pictures on the *wall::, *you know/
 48. L: =yeah/ =
 49. R: =around= the four *walls,
 50. T: but the- but the... *thing was/
 51. {[p,ac] and I *know it was-} as *one person al*luded to/
 52. was that the *pictures by [clears throat]...*what's his name?
 53. Ans-
 54. L: *Ansel *Adams?
 55. M: oh *yeah//

[Conversation moved to exchange between Tom and his daughters for the next fifty seconds, talking about the show, which featured photos by Ansel Adams of a US internment camp]

86. T: there were *ten thousand people there//
 87. L: ==what did you *think of the show/ *Rose?
 88. R: ...the *one that we saw =*here?=
 89. L: =mm/ =
 90. R: {[h] oh/} I *guess it was o*kay,
 91. ..*you know/ there was nothing.. *new or anything,
 92. except that.. you *did see pictures..of certain *areas/ and things like that//
 93. L: hmm/

94. ...did it re*mind you of anything that uh.. *you experienced here?
 95. R: *no/ because *this was all-... *you know/
 96. we'd been to {[dc] [*Tashmi, and [*Sandon,
 97. and [and (knew where) New *Denver was, *Rosebery,} and all that/ but,
 98. L: mm*hm,
 99. R: the *one that they showed that *night/ ..about two or three *weeks ago/
 100. uh..there *wasn't anything *new//
 101. L: was it *all just that one *camp then? all *photos from that just one *camp?
 102. T: yeah//

[C/RTLM.8:30 23:10- 26:15]

Although Rose's attention to this topic was engaged by Maria's orienting comment in line 9, she was not invited to contribute; indeed, initially it was not apparent that she too had gone to the show. Her contribution in line 33, relevant to Tom's criticism of the lecture, was remarkable in the context of the overall dinner-table conversation because it was the only instance in which she competed for the floor on a topic to which she had until then not contributed at all. Tom took advantage of her hesitation to move to regain control of the floor in line 35, but was countered by Linda's question to her mother, inviting her to continue with her comments. Linda's move illustrates a strategy that emerged at several points throughout the conversation, making space for her mother in the conversation by directly inviting her contribution. Nevertheless, in line 40 Tom shifted the topic back again to the lecture. This time, Linda collaborated with him, completing his sentence but then redirecting the conversation to seek Rose's opinion, again making space for her. Once again, Tom quickly regained control of the floor, although the slightly rising intonation of Rose's comment in line 49 suggested that she may have had more to say, possibly prompting Linda's renewed efforts in line 87 to again include her. Rose's request for clarification in line 88 points to her possible difficulty in following multi-party, fast-moving conversation on a specific topic, but it

also suggests her awareness of that difficulty as she attempted to keep up with the topic. The form of her response in lines 90 to 92 suggests that she knew what kind of information was requested. However, her response's lack of lexical specificity points to her inability to provide that information and may have prompted Linda to shift the topic from what Rose recalled about the show to what the show reminded her of about the past. In doing so, Linda reframed the topic from one that required explicit recall of a specific event to one in which Rose's more remote memories became relevant in themselves. Furthermore, the form of Linda's question, by implicitly contrasting the location of the show's photos with the location of Rose's own experience, allowed Rose to draw again on that experience to contribute to the conversation (lines 96 and 97). While Linda's question created an opportunity for Rose to shift the topic from the photo show to her own experience, Rose chose instead to return to the topic of the photo show, repeating her comment of "nothing new" (lines 91 and 100), this time as a move to close the subtopic of her opinion of the show. Subsequently, conversation about the show continued between Tom and Linda, while Rose and Maria engaged in a sidebar conversation about the meal, ultimately rejoining the main conversation

Competition for the floor in the conversation about the photo show highlights several features of the organization of talk in the Tanaka family to achieve specific goals. While there are examples of other ways in which Linda and Maria invited Rose's participation, the instances in the foregoing excerpt exemplify Linda's efforts to make room for her mother in a faster-paced, multi-party exchange by taking the floor herself and then using the turn to select Rose as speaker. Her repeated efforts in this respect signify her interpretation of Rose's initial contribution as an important opportunity to

include her in family talk, while her reframing of the topic to include the past suggests that the act of Rose's participation was more important than the requested information. Her moves, however, interrupted Tom's participation in a conversation that was clearly of interest to him, a phenomenon that appears to have been evident to both daughters as they supported the topic shift that he made in line 50, leading to an opportunity for him to share his opinions and for his daughters to learn more about the show itself. The conversation itself can be interpreted as a balancing act of competing goals, with topic shifts and turn-taking organized to respect the different needs of each participant.

The photo show topic also highlights another aspect of Rose's conversation, namely, the past as a preferred topic. This preference may at least in part account for why she took a more active role in this particular stretch of conversation, but it also provided her family, in particular her daughters, with a strategy for supporting her continued participation. After the sidebar conversation between Maria and Rose about dinner, (see lines 110-124 in Appendix E, Transcript 4) both rejoined the main discussion as Maria and Linda considered going to the show themselves, ultimately leading to this exchange:

Excerpt 5.28

137. L: *I just= wanna take my *time/ =
 138. M: =yeah/ *I wanna see the-= ==*we should go/
 139. {[p] *we should go//}
 140. R: yeah/ *now that they have all the *pictures *too/
 141. M: yeah?
 142. R: yeah/ black and *white,= on the *walls/ you *know?=
 143. M: =yeah/ *I'd like to see *that/ =
 144. R: and from *different *places, New *Denver, or *Tashmi, or-
 145. M: {[h] so *you were -}you were in *Rosebery/ *right mom?
 146. R: yeah/ *Rosebery//
 147. M: *Rosebery/
 148. R: mm*hm,

149. M: and you *stayed there the whole *time?
[C/RTLM.8.30: 27:01-27:15].

Maria's topic shift led to Rose holding the floor for the next six minutes, with occasional questions from her daughters, as she talked about living in the Slocan valley. They had also introduced the topic while having lunch with their mother a few months earlier, just after Maria returned from a bike trip through the area (see Appendix E, Transcript 5). It also came up in my unrecorded conversations with Rose, one with Tom also present and two just between the two of us. While its frequency marked it as a favourite topic, features of the conversation itself also marked it as such. For example, the exaggerated rhythmicity of lines 96 and 97 in Excerpt 5.27 suggested a sequence of familiar, well-rehearsed names, serving to maintain fluency despite the less certain comment with reduced intelligibility in line 97; the names appeared again in line 144 of Excerpt 5.28. Rose repeatedly used certain phrases, too, in conversation on this topic, as exemplified in the following excerpts:

Excerpt 5.29

5. M: ..where you grew *up?<2> ring a *bell?
6. <3>
7. R: *oh yeah/ New *Denver,
8. 'cause *we had to *walk about four *miles every *day from uh..
9. *Rosebery to New *Denver//
10. M: *yeah/
11. R: so =*during= our *lunch hour,
12. M: =I took- = yeah,
13. R: we'd go -I *wouldn't say down *town/ it was just a - like *these kinda/
14. um::_
15. <5>
16. L: =Rose=
17. R: =I =*liked it there/ *people were very *nice//
18. L: {[h]did your *mom...have t*b?}

[C/RLM.1.3.2:27-2:40]

Excerpt 5.30

118. M: {[h] New *Denver was nice,
 119. ..did *you spend much time in New *Denver?}
 120. R: {[h] um::}..well in New *Denver/
 121. ...we *walked the four miles from *Rosebery every *day//
 122. ..to New *Denver,
 123. M: *why//
 124. R: huh?..because we didn't *have a s- a *high school//
 125. M: *oh so it was a *school//
 126. R: yeah/ *school//..so uh.. but the *school..was right *in New *Denver,
 127. ..{[l] well you don't *call it a *city/
 128.. ..it was just a *small..*place//}

[C/RLM.1.3: 6:10-6:28]

Excerpt 5.31

1. L: but *I thought Rose was in New *Denver//
 2. R: well we went to *school to New Denver/ we *had to walk *four=*miles//=
 3. M: =mm:::/ =
 4. *every *day,..=*going,= four miles, and *four miles coming *back//
 5. M: =right/ =
 6. == 'cause we *rode from New *Denver/ **to Ro- *yeah::/
 7. *that's right/= to *Sandon//=
 8. R: =yeah/ =mm*hm,
 9. M: *okay/ *you went *to New Denver to *do that//
 10. R: yeah/
 11. M: {[pp] *okay/}
 12. R: but this *Catholic *father/

[leads to story about a priest sometimes giving them a ride home]

[C/RMLT. 8.31: 28:46-29:01]

Excerpt 5.32

1. R: *naturally we were all squeezed *in there/ but it was better than
 *walking//
 2. M: yeah//
 3. R: es*pecially in the *summer//..we had to *walk from New *Denver,
 4. <2> back- *back home to *Rosebery//
 5. M: =yeah *that's a long *walk//=
 6. R: =and *one day we = were *walking,
 [leads to a story about encountering black bears]

[C/RMLT.8.31: 29:54-30:07]

The recurrent reference to the four-mile walk from Rosebery to New Denver and back again, while repetitive, nevertheless served the interactional function of moving the conversation forward. In Excerpt 5.29, it established Rose's familiarity with New Denver, but the reason for the walk was left unexplained until nearly four minutes later, in response to Maria's question (line 124) in Excerpt 5.30. In Excerpt 5.31, Rose used the phrase again in order to correct Linda's misunderstanding of where she had lived, but it also served as an introduction to her reminiscence about the Catholic priest who sometimes gave them a ride. In Excerpt 5.32, its inclusion in lines 3 and 4 served to emphasize the benefits of the ride. The format of line 5 is a variation of a standard format for acknowledging another's authorship of a point and expressing accord with it (Jefferson, 1985). Maria's use of the acknowledgement token "yeah" in line 5 marks "that's a long walk" as something that could be understood from her mother's comment, establishing the fact of the four mile distance both as implicit and as shared knowledge.

As in the talk about the photo show, talk about the more distant past in multi-party conversations also led to competition for the floor as different participants shifted the topic to meet their own conversational needs. In Excerpt 5.29, for example, Linda took advantage of a five second pause to learn more about her family by shifting the topic to Rose's mother after allowing Rose to complete her previous utterance, as shown in the following exchange (also see Appendix E, Transcript 5):

Excerpt 5.33

15. <5>
16. L: =Rose=
17. R: =I =*liked it there/ *people were very *nice//
18. L: {[h]did your *mum...have t*b?}
19. M:<1> *no/ I don't *think so/
20. L: {[h] be*cause..I *thought} .. you *said that/

21. ..you re*membered driving *into – {[ac]..or *taking a bus *into}
 22. ..uh..**Nelson//
 23. ..they had a t*b sana- ..sana*torium? ..sana*tarium?<1> sana*torium?
 24. R: *no but..{[h] she *didn't have t*b then}/
 25. L: =[ac] then *why would she=
 26. R: =it was - = it was dia*betes//
 [C/RLM.1.3 2:54-3:16]

Talk about the past offered the opportunity to draw on collective memories, strengthening family solidarity and extending it back across earlier generations. While Rose's reminiscences were a key part of this conversational framework, Linda and Maria sometimes took control of the topic to link their mother's past to their own experience, as in this excerpt:

Excerpt 5.34

125. M: *oh so it was a *school//
 126. R: yeah/ *school//..so uh.. but the *school..was right *in New *Denver,
 127. {[l] well you don't *call it a *city/
 128.. ..it was just a *small..*place//}
 129. but actually uh..the *Roman Catholic *people/
 130. ..um..let us..have the *use.. of this..place,
 131. it- it *wasn't a *church,
 132. ..but uh..there were *people uh..uh...*what do you call/*sisters (kind of)/
 133. ..*they lived there, <2> and *next to it – the *next one,
 134. was where the..the *fathers..you know/ the *men/
 135. *they don't stay in the same *place/ ..{[p] *so it was good//}
 136. <2>
 137. M: I *like New Denver// it was a- *you've been there/
 138. L: *I went there..two *years ago//

[C/RLM.1.3 6:25 – 7:14]

In gaining control of the floor, Maria was able not only to make a link between her mother's and her own and Linda's experience, but also to shift the topic away from Rose's focus on details that seemed of little interest to her listeners. During this six minute talk about the past (see Appendix E, Transcript 5, lines 1 through 176), floor control changed frequently among the three women, with all three contributing to talk of

past and present experiences, emphasizing their solidarity through their shared knowledge of the region. Although there were other instances in which all three actively contributed to topic development, this segment of conversation was exceptional in that it was by far the longest stretch of talk during the lunchtime conversation about a topic of mutual interest to all three participants.

In summary, although Rose participated in multi-party conversations, both the quality and quantity of her talk suggested changes in the nature of that participation. During the lunch and dinner conversations with family members, she participated throughout by taking part in organizational conversation around the meal itself. In talk on other topics, however, conversation more often flowed with few pauses among the other participants. In multi-party family conversations, individual participants may feel little social obligation to contribute to talk, particularly when there is competition among others for the floor, so that Rose's silence could be interpreted as a choice. However, the actions of Rose's daughters in particular, including inviting her participation through direct questions, introducing favourite topics, and gaining control of the floor from others in order to make conversational room for her, suggest that for them her lack of participation was not by choice, but rather marked a need for support. This interpretation invites consideration of Rose's participation in two-party conversations, in which there is typically less competition for the floor, but more obligation for each participant to contribute to talk.

Two-Party Conversations: Differences in Obligatory Talk

Two-party conversations with Rose were recorded on two separate occasions, with the first taking place during a visit with Maria, who had come over to keep her

mother company while Tom was out, and the second taking place between Rose and Tom during dinner at home, a routine everyday event. Differences between these two conversations reflect, in part, the differences in social obligations associated with each type of event, but they also reflect differences in the conversational goals, strategies, and expectations of the participants, described earlier in findings from the interview data.

The conversation between Rose and Maria was similar to the “small talk” conversation described earlier in that much of it was motivated by the status of the occasion as a visit. There was only one silence lasting more than a few seconds, which occurred while Maria was writing a note for her father; a silence that Rose ended with a question:

Excerpt 5.35

1. M: *I'm just leaving a *note for *Tom,
2. R: {[pp] mm*hm,}
3. {[sound of writing on table] <40 >}
4. R: y' *want more *paper?
5. M: {[h] no_} <2> {[p] *I just left a *note//
6. {[intermittent sound of paper rustling] <25>}
7. R: {[h] *how's your *business doing at uh}...#name of business#//
8. M: ...it's been *good/
9. R: {[p] it's *holding its *own/ and *everything? *that's good//
10. M: ==yeah I'm -
11. I'm *planning right *now a ten year anni*versary//
12. R: =hmm/=
13. M: =in = De*cember,
14. R: oh/
15. M: so_
16. R: ten *years now/ eh?
17. M: mm*hm/
18. R: =*gee:::// =
19. M: can *you i*ma=gine?

[C/RM.3.16. 23:56 – 25:28]

Line 7 is remarkable in that it represents the only instance in all the recorded conversations where Rose initiated a new topic with a question about her conversation

Again, Rose's question in line 9 and her follow-up comment in line 11 are remarkable only in that they are exceptional, rather than representative, in the overall conversation.

While the talk between Maria and Rose was in some ways similar to the small talk of my conversation with Rose and Tom, it differed in that it drew much more on their shared knowledge as the two talked about recent events involving other family and friends. It also included goals beyond the talk itself, as in this excerpt about an upcoming wedding:

Excerpt 5.37

1. M: but *we'll see each other at..at the *wedding/ *anyways//
2. R: *yeah::/
3. M: ..and I'll *bring your *dress over be*forehand/ so/
4. R: {[p] what dress is *that//}
5. M: the *pink dress/
6. ...that..we're getting *cleaned=for you/ for the *wedding//=
7. R: =oh..oh *I see/ yeah/ =
8. M: so... *we just have to *find you a -
9. R: ==*sure/
10. M: ==a-
11. I'm *sure you have a *slip in one of them/..=closets, =
12. R: =*oh yeah/=
13. I *do have/ yeah//
14. M: {[p] yeah//} <2> and you've *got some -
15. do *you have some comfortable *shoes?
16. {[h] oh::/ *I had some *flat sandals that you *liked//}
17. *I should *bring them//
18. R: =the *white one? =
19. M: ='cause *you had-= yeah::/ the *white one//
20. you *liked those/ *didn't you?
21. R: {[h] yeah/ *they were comfortable,}={[p] yeah//}=
22. M: =yeah/ =
22. *no/ but = I don't wanna - =
23. M: = (they'll *do with the)=*dress you're wearing//
24. R: I *don't wanna take it a*way/ if you're -= if *you-=
25. M: =*no::/ =
26. *I'm not gonna be *using = that//=
27. R: =oh = oh *I see//

28. M: {[p] yeah//}
 29. R: {[pp] mm*hm//}
 30. M: ...*I'll bring it..*over::/{[p]..I'll have to re*member that//}
 31. ...on *Fri::day//...{[pp] *yeah/ *Friday//}
 32. R: {[pp] mm*hm,}
 33. <2>
 34. {[f] *or::,}
 35. ...if you *happen to be coming to #business#/ for some *reason,
 36. M: {[p] mm*hm,}
 37. R: {[p, l] *maybe you want to use their...what*ever it is/
 38. you could ..*leave it *there, and then I'll take it *home/
 39. M: mm*hm,
 40. R: ..from #business#//
 41. M: {[p] mm*hm/} *could do/

[C/RM.3.9: 13:29 -14:39]

Several features of this talk warrant consideration. First, in the overall data set of recorded conversations, this excerpt was one of very few instances in which Rose actively collaborated (lines 34-41) in planning for an upcoming event. Second, neither her forgetting the dress (line 4), which had been discussed a few minutes earlier, nor her word-finding problem (line 37) interfered with the flow of the conversation. In the first instance, Maria provided the information that Rose requested; in the second instance, the failure of both women to seek a repair marked the detail as irrelevant, so that a repair was not required. Shared knowledge of the upcoming wedding, the shoes, and the possibility of Maria dropping by her sister's business marked this as talk between familiar partners constructing their closeness again in conversation.

In contrast to the nearly continuous conversation between Maria and Rose, the dinner conversation between Rose and Tom was characterized by stretches of talk interspersed with relatively long silences. While some of those silences appeared as punctuations in conversation associated with the activities of the meal itself, many of them could be interpreted as a sign of intimacy, marking the couple's dinner together as

an everyday event that offered an opportunity rather than an obligation to talk. The pattern of conversation at dinner was generally short stretches of talk on a topic, usually initiated by Tom with varying levels of participation from Rose, followed by silences up to one or two minutes, then a new topic. Analysis of the moves from talk to silence, however, suggests that it was not always a positive sign of intimacy, as in this excerpt:

Excerpt 5.38

- <62>
1. T: [clears throat] *we might be leaving for [clears throat] our *trip/
 2. ...as early as... next *Thursday or so/ you *know?
 3. ...because if *we're not going to *Reno,
 4. {[eating] <11>}
 - 5.. mm..we might as *well/
 6. {[eating] <5>}
 7. go at any *time//
 8. ..*you know,... we don't have to *go/..between *Sunday..and *Thursday/
 9. when accommo*dation is very.. *cheap//
 10. {[eating] <10>}
 11. do you *remember who..we're *going with?
 12. <3>
 13. R: *no/..'cause I *didn't really *know wh-
 14. who was *going, or what was *happening/
 15. so/
 16. {[eating] <12>}
 17. T: we're *going with..*Mary and uh..*Dean//
 18. R: mm//
 19. <93>
 20. T: do *you uh/ [clears throat] re*member who was *here to*day?
 21. <3>
to the *house?

[C/RT.4.15.15:05-16:48]

Tom's question in line 11 was motivated possibly by the absence of any comment or backchannelling from Rose. In light of his observations during the interview about the variability in Rose's behaviour from day to day, as well as his speculation about whether or not she was listening to him, his question marks both the absence of an expected

response and his effort to understand that absence. Rose, in following up her response with an account, preserved face by claiming, not that she did not remember, but rather that she didn't know. In doing so, she denied Tom's implicit claim that the information was part of their shared knowledge. Tom's choice not to pursue the topic beyond line 18 both reflected and reinforced his assumption that there was no point in trying to plan with her, positioning the subsequent ninety-three second silence as an absence of talk, rather than a companionable intimacy.

While the foregoing excerpt exemplified Tom's difficulty in achieving the conversational goal of planning an event together, it was not representative of Rose's participation across the entire conversation. In other instances, she too collaborated in the construction of talk, as in this excerpt (See Appendix E, Transcript 7):

Excerpt 5.39

[Tom introduced a new topic of their recent trip to a casino. After a 12 second silence, Ruth extended it as follows]:

12. R: um...[clears throat] {[h] *those people..uh...that *own that thing/}
13. T: what/..the ca*sino?
14. R: ca*sino/ =yeah// =
15. T: = {[pp] yeah//=
16. <2>
17. what a*bout them//
18. R: well *maybe not the *building/ if they have to rent it *out/ but-
19. T: the *business/ {[pp] yeah,}
20. <2>
21. T: what a*bout them//
22. R: so {[sound of cutlery] <3>}
23. {[h] um::} <2> they could *have those..ca*sino kind of like *thing//
24. ...they *have to have a certain *license/ *don't they?
25. T: yeah::, they *have to get the okay from the *government to *operate//
26. [clears throat] *not only *government/..I guess the... [hhhh] *city *too//
27. <9>
28. T: they *say about *five percent.. of the *people have *trouble/
29. ..*problems/ with the gambler// ..*you know/ gambling?.
30. R: *oh::/.I *see//
31. T: getting - *problem gamblers//

32. <18>
 33. T: {[h] *I often *wonder} how some of those **young... *people/
 34. R: {[ppp] (how they *do it?)/}
 35. T: with uh - *you know/ *wads of *money/
 36. *five hundred *dollars/ a *thousand *dollars/
 37. <4>
 38. *how they uh/ <3> can af*ford it/ you *know?
 39. <12>
 40. R: *I was uh- *I was ama- I was *just kinda-
 41. [clears throat]*I wasn't looking over their *shoulders/
 42. but I was *looking.. at a certain *tables/ that they were on,
 43. ...and I was a*mazed how -..uh..so many *young people//
 44. T: oh *yeah/ {[ppp] yeah//} and *that was in the middle of -
 45. ...well *not middle of the *day/ but uh:... *obviously/.
 46. .they're not *working//
 47. R: or they *could be *high school boys,
 48. uh...I *guess they make some *money *working,
 49. and they *use that money to ..to *gamble I think//
 50. T: {[pp] mm//}
 51. <9>
 52. *lots of young - well I wouldn't say *lots/
 53. but a *few *young... **women/
 54. mostly Chi*nese/ =you *know?=
 55. R: =yeah, .. = I *noticed =that// =
 [Both continued this topic for another 14 turns]
- [C/RT.4.21 18:49-23:53]

Although Tom's introduction to the topic of gambling focused on a particular event, Rose's extension of that topic drew more heavily on her general knowledge of gambling. The contrast between this excerpt and the preceding one points to differences in the demands that each placed on episodic (i.e., event-based) versus semantic (i.e., fact-based) memory; Rose's relative participation in each conversation is consistent with findings that conversations which place more demand on episodic memory are particularly challenging for individuals with AD (Orange & Purves, 1996; Small & Perry, 2005).

A second point to note with respect to this more interactive conversation is the strategies used by each participant to keep it going. First, Tom supported Rose in establishing the new direction of talk, first by his repair in line 14, then by his prompts in

lines 17 and 21. Each of those turns focused on clarifying the content of her talk, suggesting the importance of coherent information exchange. However, his next turn, (lines 25-26), including first affirmation and then an extension of the topic to problem gambling acknowledged the interactional significance of Rose's contribution as an effort to extend the conversation. Rose herself used the strategy of incorporating fragments of Tom's talk into her own (see, for example, lines 33 and 43) but she also added her own speculations (lines 47-49), finally shifting the topic again (line 69) to horse racing, a move which Tom chose not to follow. Altogether, the excerpt illustrates one of the more collaborative constructions that occurred in the couple's conversation and points to their mutual awareness of dinner together as an event that permitted silence but also carried some obligation to talk.⁹

Two-Party Talk: A Challenge to the Management of One-sidedness

The one-sidedness of conversation with Rose described by family members referred not only to her lack of participation, but also to her tendency to talk about topics that were not always of mutual interest to her listeners including, in particular, retellings of stories of the past. While Rose's stories of the past emerged in several conversations, they were particularly noticeable in the two-party conversation between her and Maria. During her interview, Maria described the past both as a topic that her mother enjoyed talking about and as one that offered the possibility for her to learn more about her own family, so that she was willing to encourage Rose to talk about it, as in this excerpt:

⁹ It must of course be acknowledged that the presence of the tape recorder at dinner could well have contributed to their awareness of an obligation to talk. At the same time, their selection of dinner conversation as an occasion for taping marks it as an event where some talk could be expected to occur.

Excerpt 5.40

1. R: y' know/ something like *this/ it doesn't *matter if you eat a lot/
2. it's *not as if you're eating refined *sugar/
3. you know *sweet stuff =or anything=/
4. M: =*mm// =*seaweed and *salt/
5. {[h]*didn't your *mom used to make *seaweed?}
6. R: *I used to *help her/
7. M: really?
8. R: even be*fore the war/
9. I used to – I was – it didn't *matter to me because-
10. uh... *dad had a big *boat/... 'cause *his boat wasn't a *fishing boat/
11. it was a *fish packer//

[C/RM.3.26. 38-37-38:49]

Reminiscence about her father's boat led to a story about him, given in its entirety in

Appendix E, Transcript 6. Analysis of that narrative suggests that, though it may seem to have been one-sided talk, it was nevertheless a collaborative construction in which Maria supported her mother's telling by positioning herself throughout as listener, exemplified in the following excerpt:

Excerpt 5.41

1. <3>
2. R: the *only thing *is that one *time near Prince *Rupert/
3. the *storm was coming *in/..so he was- says **oh:: my **go::d/
4. I'm gonna *drift..towards a- A*laska//
5. and there were a lot of *fishing boat/..from U S *fishermen/
6. *somehow,..because the *storm was so *bad/
7. they kinda *came towards the..*British Col*umbian water//
8. M:mm*hm/
9. R: and he said *god they were awful..*drivers/
10. they *didn't seem to *care//
11. ...um <2> and *then,
12. <2> {[h] the *second time} he said was so *queer,
13. was that... *his boat was taken a*way/
14. *all Japanese *fisherman got their *boat taken away//
15. M:hmm/
16. R: and they *weren't given a *penny//
17. M: {[ppp] yeah/}
18. R: and *then he says_...he was a *little bit out*side the *water//

[C/3.27: 41:00-41:47]

In this excerpt, lines 1-7 introduced the narrative in giving the setting and characters. The positioning of Maria's backchannel in line 8 was typical (though not exclusively so) of her use of it throughout the narrative, serving both to acknowledge the introduction and to encourage her mother to continue. Lines 14-17 marked a relevant digression, eliciting more backchannelling from Maria in acknowledgement of the information, with Rose returning to the main story in line 18. Throughout the ten minute narrative, Maria's contributions were all structured so as to encourage her mother to continue, including either backchannelling (lines 34, 36, 42) or collaborative efforts to repair breakdowns signaled by Rose (line 44), as in this excerpt:

Excerpt 5.42

30. R: „and *then he says he looked *up/
 31. <2> {[dc] 'cause there was *so much *water, and *wave,}
 32. ...and he says- {[h] he says {[~] *that's my *new **island/
 33. *that's my **boat//}
 34. M: {[ppp] hmm/}
 35. R: the *fish packer boat was *taken...=a*way/ =
 36. M: =mm*hm/=
 37. R: from the =*federal=*government,
 38. M: =(xxx) =
 39. R: but the *federal *government just *gve them a*way/
 40. *all the Japanese *boat were given a*way//
 41 and *those people *pocketed/..=the =*money//
 42. M: =[pp] yeah//]=
 43. R: and *he said he *saw this *Vancouver-..the- .the:: _
 44. ...{[p] *something *island it was called/
 45. M: ...{[p] *sea island? [ppp] no/
 46. <3>
 47. R: {[h,pp] *isn't it *funny/..*Vancouver-}
 48. ..well *anyway/..but *he says/
 [C/RM.3.27: 42:25-43:01]

Because Rose initiated the repair attempt that took place in lines 44-47, Maria's efforts to help her can be interpreted as an effort to facilitate a return to the main narrative. The

breakdown-repair sequence is particularly interesting because a few seconds earlier, Rose had presumably given the name of the boat (line 32). This suggests that, though Maria's collaborative behaviour indicates that she was listening, her attention may not have been fully engaged.

While Maria's collaborative listening strategies were relatively consistent throughout the narrative, the narrative itself varied considerably in overall coherence. In the first part (lines 1 - 95), there was a coherent story line describing how Rose's father rescued a fisherman who was, coincidentally, on a boat that her father used to own. At the close of that story, however, Rose began another story about how other fishermen tried to take advantage of her father, wanting to borrow supplies from him. The story shifted several times, however, and, although there is local cohesion within phrases, there is an overall incoherence:

Excerpt 5.43

185. R: *so...uh..when my f-..uh..uh. *father uh.. *talked to him,
 186. and *tried to tell him/
 187. {[h] *okay/ now you a*pologized, you've *learned your *lesson,
 188. and *hopefully/ you grow up to *be/..what you should *be//
 189. .and *this little boy started to *cry::, and he says..he says/
 190. *I don't think I could go *home, and tell my..*parents/ what I *did//
 191. .so my *dad says/..{[ac] *okay/..*don't worry/}
 192. *you and *I will just *go home/..go *over to your *place/
 193. ..told them e*xactly what had *happened,..and I said your *son,
 194. he was *quite *brave,.. he a*pologized,
 195. ..he a*pologized to my *father *too//
 196. to *say that he..*just wasn't *thinking//
 197. M: yeah/
 198. R:and he says/ #name#san,..he says/ *I learned a *lesson/ so she says/
 199. I'll *never,..for*get you/ he says/ I *really **learned something today/
 200. =so- =
 201. M:={[dc] he = *seemed like a...*really..{[hhh] *wise **man/}
 202. <2>
 203. *I don't know if To-..I *think Tom is going to be home at *seven Mom,

204. R:most *likely//

[C:RM 3.27/28. 49:03-50:10]

Although at the start of this narrative (lines 97-187) the person who was apologizing to her father was a fisherman, by line 189 Rose was talking about a young boy; the apology through the story evolved from one made to her father to one that her father encouraged someone else to make to another fisherman, to one made to him by a young child. Maria made fewer acknowledgements to support her mother's narrative as it became increasingly incoherent until finally, in line 201 she chose to discontinue, bringing a close to Rose's narrative by offering an evaluative coda that acknowledged its overall meaning.

Maria's willingness to support her mother's narrative was an acknowledgement of its importance for Rose and an implicit recognition of the value of reminiscence in the construction and presentation of self. Her collaborative support in constructing that narrative, by employing devices to facilitate continuity without attempting to redirect it, placed her mother's reminiscence over her own goals of learning more about the family past.

Summary

Several key findings that have emerged from the analyses of talk, including both interviews and conversation, inform our understanding of the Tanaka family's experience of Alzheimer's disease. Interview findings highlighted how each individual, including Rose, incorporated the diagnosis of AD into explanations and expectations of perceived changes in her behaviour, but they showed also how patterns of similarities and differences in accounts characterized the three adult children as an integrated sub-unit of a close-knit family. With respect to the diagnosis, this sub-unit stood apart from, though

in strong support of, each of their parents, separated themselves by their own differing interpretations and responses to the diagnosis. Analysis of the family's conversations sheds light on how, in the context of a diagnosis, conversational behaviours such as, for example, forgetfulness, take on the status of symptom, leading to a different response than might otherwise occur.

Another key finding of these analyses was the moral distress experienced by the family. Although the diagnosis of AD offered some legitimacy to actions that may have violated Rose's autonomy, family members sometimes questioned whether they were taking over too much. Discontinuities between attitudes towards Rose as a person with AD versus Rose as wife and mother were evident in differences between talk in interviews where all, including Rose, acknowledged her AD, and talk in everyday conversations together. In conversation, family members' accounts often attributed changes in role (e.g., cooking) to factors other than AD, allowing Rose to maintain familiar roles even if no longer maintaining the activities associated with those roles. At times, however, such accounts no longer sufficed (as, for example, in Colin's challenge to her ability to sustain her role as caregiving grandmother).

Lastly, findings shed light on the nature of family conversations and changes associated with AD. A key finding was the individuality of each family member's conversational relationship with Rose, which was particularly striking in view of the relative consistency of other family accounts, and highlights the family as a network of interactive relationships among individuals. A second finding furthers our understanding of loss associated with changes in conversation. Analysis of conversation showed how all family members, including Rose, found ways to facilitate their talk together despite

the cognitive changes associated with AD; overall, there were few instances where interlocutors signaled talk as problematic, and even fewer that were not successfully resolved in the interaction. Yet despite this relative success, interview findings revealed how all family members, except Rose, experienced changes in their conversations with her in terms of loss. Together, these findings highlight how conversation is intimately interwoven with relationship; loss of familiar patterns of conversation threatened each individual's relationship with Rose.

Commentary

For the Tanaka family, interactions with Rose represented interactions not with a person with Alzheimer's disease, but with wife and mother. Analysis of conversations in a family identified because one member has Alzheimer's disease necessarily adopts the perspective of viewing that person *as* a person with AD. However, the analytical focus on Rose as a person with AD risks overshadowing the family's perspective of Rose as wife and mother in their everyday interactions. Within the analytical framework of Alzheimer's disease, it is not only behaviours that are typically associated with its symptomatology that invite consideration; behaviours that might otherwise pass unnoticed in everyday family life, that occur in the "just a normal day" of Tom's account, take on meanings that may not be evident at the time to the participants themselves. Yet it is the consideration of these different types of behaviours together that frames the overarching theme of the Tanaka family interviews and conversations, that is, their struggle, individually and collectively, to come to terms with Rose's AD in ways that could integrate their constructions of her as wife and mother with their constructions of her as a person with Alzheimer's.

Acknowledgement of the family's struggle sheds light on several important aspects of how family life was constructed through its talk, but also how family life was influenced by that talk. Undeniably, Alzheimer's disease affected Rose's ability to maintain activities associated with long-standing roles in family life. Attention to family talk reveals how evolving roles and relationships were negotiated among all family members as they tried to come to terms with Rose's Alzheimer's. An important point here is that, in discursive approaches to understanding social interaction, roles are not fixed, determinate categories. Rather, they are constructed through talk that positions participants in particular ways, thus allowing for "a diversity of selves" (Davies & Harré, 1990, p. 47). As Davies and Harré point out, positioning oneself and others in interaction is not necessarily intentional, nor is it necessarily consistent; it is a dynamic process that positions not only the other but also, relative to that positioning, oneself. Harré and Langenhove (1991) developed the concept of positioning further, differentiating several varieties of positioning, all of which can be exemplified by findings from the Tanaka family conversations. These include first order positioning in which, by their utterances, "persons locate themselves and others within an essentially moral space by using several categories and story-lines" (p. 396). The implication here is that the person who positions the other in a particular way has (or thinks she has) the moral right to do so; this moral right is usually linked to people's social or institutional roles. In the Tanaka family conversations, Rose was positioned, both by her own and others' talk, in numerous ways, for example, as mother, as grandmother, as cook. First order positionings, however, were not always accepted by the other interactant(s), necessitating accounts and negotiation. Harré and Langenhove refer to this as second order positioning, which

occurs when a first order positioning is questioned by another interactant. Although the assumption of moral rights can itself be challenged, second order positioning often moves the interactants from moral to personal positioning, in which particular circumstances or characteristics are used as accounts to justify and negotiate deviance from an expected position. The Tanaka family conversations presented numerous examples of second order positioning, as participants' positioning of Rose was sometimes contested, sometimes mitigated, sometimes supported by others. It is in second-order positionings that the family's efforts to come to terms with Alzheimer's disease were most evident, as they tried to negotiate between positioning Rose as mother or grandmother, for example, with positioning Rose as a person with Alzheimer's, entailing a different set of rights and obligations. In everyday conversation, these positionings were mediated by numerous contextual circumstances, so that at different times, participants engaged in first and second order positioning in diverse, inconsistent, and sometimes contradictory ways.

Finally, in Harré and Langenhove's varieties of positioning, there is third order positioning, which is based on instances of first and second order positioning but occurs in talk outside of that in which those positionings took place. In third order positioning, new story lines are created that can be used to locate persons differently within moral and social space. Such third order positioning occurred in the Tanaka family talk about Alzheimer's (i.e., in interviews), positioning Rose as a person with AD and, less consistently, Tom as a caregiver. In this talk, a strong sub-unit comprising the three adult children emerged, characterized by shared understandings of the diagnosis and its implications, as well as by shared efforts to support Rose and Tom within these new storylines. Nevertheless, in everyday conversations, this was just one of many storylines

that shaped interactions. Furthermore, even the storyline of Alzheimer's was complicated by inconsistencies as in, for example, conversations that alternated between disordered and "just normal", forcing family members to constantly reframe their interactions with Rose. For Tom, living with Rose, the unpredictability of disordered talk was particularly marked, and may have contributed to differences between him and his children in their interpretations of Rose's conversational behaviours as symptoms of AD.

In addition to positioning oneself and others in a multiplicity of roles, talk is also fundamental to sustaining and supporting relationships within those roles. Rose's conversational abilities were disrupted by Alzheimer's disease, resulting in, for example, repetitiveness, word-finding problems, and the forgetting of shared knowledge; her family also attributed her diminishing participation in conversations to AD. These problems could all be identified in family conversations, but the family's strategies for coping with them were also, for the most part, effective. In response to her memory problems, for example, family members found ways to include additional contextualizing information; in response to her diminishing participation in conversations, they found ways to include her. The combined analyses of conversations and of interview data together inform our understanding of why, despite these apparently successful strategies, conversations were characterized so consistently as problematic. First, the analyses emphasize the individuality of each conversational dyad, portraying the family as a complex interaction of particular relationships. Clearly, each person in the family continued to find ways to have conversations with Rose that might be considered successful in the context of conversations with a person with Alzheimer's, but they were not considered successful in the context of conversations with Rose as that person's wife

or that person's mother. For these family members, disruption of conversation with Rose meant disruption of the particular kinds of conversation that were part of each individual's long-standing relationship with her.

CHAPTER SIX

THE THOMPSON FAMILY AND PRIMARY PROGRESSIVE APHASIA

As with the Tanaka family, three topic areas were explored with the Thompson family, including Margaret (diagnosed with PPA), her husband John, daughters Angela and Christine, and sons Stephen and David, both through interviews and through their conversations. These topics included progressive aphasia as a diagnostic entity, changes in family life associated with that diagnosis, and changes in conversational interactions associated with the diagnosis. In this chapter, findings within each topic area will be presented in two ways, first describing participants' understandings as represented in interviews and, second, describing how patterns and themes emerging from the interview data were constructed in family conversations. A final summary will address the research questions with regard to the Thompson family, followed by a commentary that will highlight and integrate key points from these analyses.

Primary Progressive Aphasia: Diagnosis and Uncertainty

Interview Representations of PPA as Diagnosis

The Process of Diagnosis

In contrast to the Tanaka family, in which the whole family was involved in seeking a diagnosis, only Margaret and John were involved in that process, with the rest of the family learning of the diagnosis from them. Margaret commented to me that her

problems began six years earlier, when she had, in her words, "suffered a speech deficit" [IM: 110]. This worsened over the next few years, particularly in the previous two, eventually prompting her to consult a neurologist. John, acknowledging that Margaret had been aware of her word-finding difficulty for much longer than he had, apparently first identified it as a problem approximately three years prior to diagnosis. He first linked Margaret's word-finding problem to an earlier episode of insomnia, for which she had begun to take medication. An Internet search suggested a connection between speech difficulty and the medication she was using, leading him to question the possibility of that being a cause, and to support Margaret in seeking a diagnosis. Ultimately, they were referred to a multidisciplinary clinic that specializes in the diagnosis of Alzheimer disease and related disorders, where Margaret was given a diagnosis of primary progressive aphasia.

For the Thompson children, there was a growing awareness of Margaret's word-finding difficulties, both through reports from their parents and from their own observations. Angela was not aware of her mother's word-finding problems until her parents told her specifically about them; noticing them herself firsthand when her parents next came to visit. Christine too began to notice her mother's word-finding problem only after her mother complained to her of it, but at first considered it to be normal: "I always thought/ well often *I find myself reaching for words," [IC: 228]. However, she did not maintain this parallel over time: "but it- it has..changed noticeably/ in the last uh..{[p] say the last year and a half or thereabouts" [IC: 230-231]. David, seeing his parents much more regularly than any of his siblings, also attributed his mother's word-finding problem initially to normal processes: "I mean everybody's at a loss for words..at times/" [ID:

108], but he then observed a noticeable change over the next few months. For David, “noticeable” was substantiated by friends who occasionally saw his mother and commented on the changes in her speech. Stephen also was aware of his mother gradually becoming “quieter and quieter” [IS: 131], but attributed it to her insomnia and possible depression. His awareness shifted when “all of a sudden – this would’ve been ..I guess like maybe two and a half years ago/ three years ago/ there was..concern about her not being able to talk as much/” [IS: 132-135].

For all four children, once they were aware of Margaret’s word-finding problem as a problem, they interpreted it as part of other problems that they knew about, including her insomnia, as well as anxiety and some depression. For each of the four, the diagnosis of primary progressive aphasia, therefore, represented a disjuncture of perceptions and understandings. Angela commented that, for her, “it [the problem of communication] seemed to emerge” [IA:71] within the context of investigations into Margaret’s other complaints. Her understanding changed as more news came from her parents: “in my dad’s opinion/ that..that *yes there was a problem/ but it had pla**teaued/ and I was under that impression for a long time/ that it had plateaued/” [IA: 90-91]. This representation of her mother’s condition was in sharp contrast to the final diagnosis, so that for her, the most significant part of the diagnosis was the realization of the progressive nature of her mother’s condition: “they..came back/ and told me/ that it’s..progressive/ and that it will..uh..go on/ {[p] uh..getting worse/} [IA:98-99]. The diagnosis represented a shift in her understanding and expectations: “that’s when I knew there was no –no going back/”[IA: 101].

For the Thompson sons, too, the diagnosis was unexpected. Stephen had been aware that his mother had a small tumour (an acoustic neuroma, according to John), which he thought was related to “a whole bunch of things” [IS: 129], including insomnia, depression, and, at least initially, his mother’s decreasing talking. Although he was aware of changes in his mother’s communication, there is an element of surprise in his account of learning of his mother’s diagnosis: “I got updated once in a while, I come over once in a while, but one day, my father just told me, that there was a diagnosis/” [IS: 141-142]. The diagnosis was not consistent with his expectations: “Before that/ this actual diagnosis came in/ and I understand this is the correct diagnosis/ before that diagnosis came in/ I didn’t think she had – it was a speech- really a speech problem/” [IS: 115-117].

David too described different expectations concerning his mother’s diagnosis. Although he had known she was going for some sort of tests, he was not really aware of what they were, anticipating that his parents would tell him more if necessary. He explained:

“I had ex...expected that if she was dealing with a psychologist, or a psych- psychiatrist, that they were going to..find/ that it was-...had something to do:: with a more – more of a mental condition/ rather than a-..a physical/..uh. medical condition/” [ID: 153-155].

Diagnosis as Explanation: Representations and Mismatched Perceptions

All members of the Thompson family represented the disorder of primary progressive aphasia in terms consistent with clinical descriptions. Margaret, for example, described it as “a- de- degenerative of..um/..deficit of- of the uh language..side of the brain/ this side/” [IM: 85-86], pointing to the left side of her head. Stephen and David too described the disorder as affecting specific parts of the cortex. While everyone

acknowledged the progressive nature of the disorder, for John, like Angela, it was particularly salient: "and:: it was of course the word progressive/ immediately..shot up red..flags all **over the place/" [IJ: 62-62], explaining further: "we already knew/ that it was called aphasia/ but um:: most aphasias are not of that..sort/" [IJ: 70-72]. Yet, despite apparent similarities in family members' descriptions of the disorder, the ways in which they interpreted the diagnosis as an explanation for observed changes in Margaret were substantially different.

For both John and Margaret, the diagnosis of primary progressive aphasia was reified to a considerable extent, with the name itself repeated frequently in both interviews. Both accepted it as an explanation for Margaret's communication problems. They also used the diagnosis strategically to ameliorate social interactions with others. John explained: "I feel it **necessary/ practically/ if I'm around/ to jump in/ and **tell them/..what the problem is/" [IJ: 1319-1320]. He used this strategy even more proactively, informing friends and family in their annual Christmas card of Margaret's diagnosis. Margaret voiced her appreciation of this step in describing how she received many replies from people expressing their support for her.

Yet, for John in particular, it was a diagnosis that led more to questions than to answers. He described his search, primarily on the Internet, for a cause for the disorder, having alternately considered the possibility of medications, a stroke, and even, drawing on the analogy of a more distant relative with an acute-onset neurological problem, a virus. He expressed his frustration at never having met or heard of anyone in his acquaintance who had the disorder, so that he was neither able to draw on any personal experience of others within his community, nor to share his own experience with others

in the same position. His primary source of information was an American website dedicated to primary progressive aphasia and its links to related sites. Although he learned from these, his description of the contents suggests a lack: "everything from uh..virtually medical rounds type stuff/ to uh.kind of descriptions of ..various peoples' experience with it// all of which/ helps understand/ uh/ but it's uh..it's not a huge thing/ the way Alzheimer's is//" [IJ: 328-333].

In contrast to John, each of the Thompson sons and daughters showed much less tendency to reify the diagnosis. Angela did not talk about the diagnosis itself, beyond emphasizing the impact of the word "progressive". She described her mother's problem more in terms of her own observations: "it took her awhile/ to..put her thoughts together to answer/ and sometimes she'd use the wrong word/" [IA: 85]. David, while describing primary progressive aphasia in clinical terms, simultaneously disclaimed familiarity with it as a diagnostic category:

"you won't be able to get me to..to say the name/
because I keep on forgetting the name/
uh..the only part I remember for certain/
is that it's some sort of aphasia// um:...from what I understand,
it is a..disorder that continually gets worse,
from what I also understand,
it's only supposed to affect..part of her brain/"

[ID: 9-11]

However, for David, the diagnosis itself was insufficient as an explanation for his mother's word-finding problem, which he linked to other aspects of her personality:

"personally..I had always..sort of made a connection/ that there was something there/ some unresolved stress and issues that weren't dealt with/ that kind of had an impact on her/" [ID: 296-298]. This explanation was offered somewhat tentatively: "whether I'm correct about that, I just..made that observation/ I've really noticed it/" [ID: 300], perhaps

in part because of the reaction of other family members to whom he mentioned the possibility: "I didn't really get much of a response/" [ID: 302].

While David may have felt alone in his family in linking his mother's word-finding problems to stress, Christine's explanation resonated strongly with his. Alluding to her background knowledge of psychology, she characterized her mother's diagnosis in clinical terms: "some uh..brain disorder/ perhaps originating from a small stroke/ I believe it's maybe Broca's area/" [IC: 12-13], while also acknowledging its progressive nature. Although Christine accepted this as an explanation for her mother's word-finding problems, she, like David, linked the diagnosis to her mother's stress. In her account, however, there was a more explicit causal link: "if it's something like a lifetime/ of always being..you know/ keyed up/ has just caused something to ..to snap/" [IC: 29-30].

Unlike his brother and sister, Stephen did not link the diagnosis of primary progressive aphasia to problems other than those attributed to it, (i.e., her decreasing ability to talk). However, his interpretation of the diagnosis was not entirely consistent with his own understanding of his mother's problems. He recollected that, when he first became aware of the concern around his mother's decreasing ability to talk, he interpreted her inability as trouble remembering words: "that's what I thought// remembering words/" [IS: 138]. He was clearly aware of clinical descriptions of primary progressive aphasia, explaining: "I understand there's s- some part of her..actual..in her brain/ or part of her cortex that's..disintegrating/ and it's only specific to one area of her cortex/" [IS: 24-27] and that "they say that it's progressive/" [IS: 29]. He also was more detailed in his description of the nature of his mother's word-finding problems than others in the family:

"sometimes she can formulate something/ she can..say something/
 but it seems like she's ..premeditated it a bit/
 and then..it comes out real clear//
 ..just a very succinct thought that comes out/ a whole thought/
 but it comes out very succinct//
 but if you have to-she has to *improv something/
 that's right off/ you know/ just react to something/
 it doesn't come across that easy for her at all//"

[IS: 68-76]

Drawing on knowledge of aphasia from psychology courses that he had taken, he interpreted Margaret's word-finding problems as involving motor control: "you have these words in your mind, but you can't actually get your lips to say them//" [IS: 78-79]. His interpretation of aphasia in these more physical terms was at odds with his earlier assumption of a problem in remembering words, and perhaps explained an assumption revealed in another statement: "she at least has the **rest of her health, and I- I think that she- her **mind is fine" [IS: 53].

Taken together, family members' differing interpretations of the diagnosis of primary progressive aphasia, despite relatively similar descriptions, suggest that the lack of public representation of the disorder in terms other than clinical description could be used to advantage, while in other ways it was problematic. For the Thompson parents, the lack of public awareness of the diagnosis provided an opportunity to represent it to others in terms that were most supportive of Margaret's abilities and needs. At the same time, the lack of public awareness increased their sense of isolation in coping with the disorder as they had little or no opportunity to reflect on their own experiences in the context of the experiences of others. The absence of that broader context may account for the differing interpretations given by the Thompson children, as each tried to

reconcile the diagnosis with his or her own experience and understanding of their mother's condition.

Diagnosis and Uncertainty: Alzheimer's Disease and Unknown Expectations

A theme that emerged in several of the interviews with the Thompsons was the relationship of primary progressive aphasia to Alzheimer's disease. The question of Alzheimer's may have been to some extent prompted both by the name of this project, which obviously came up in my first meeting with each family member and which itself suggests a link between the two disorders. However, individual family members responded quite differently to the topic, suggesting differences in their sensitivity to the possibility of such a link. Neither Angela nor Christine raised the issue at all. Stephen brought it up as a question while reading the consent form prior to our interview, asking: "Is this disorder related to Alzheimer's?" [IS: 1]. He explained that he understood that his mother had a progressive disorder but differentiated it from Alzheimer's, explaining: "but I thought..with Alzheimer's is more all encompassing/ did more memory loss/" [IS: 11-12]. He also acknowledged that he had previously considered the possibility of Alzheimer's: "I thought about it before/ when I thought my mom was losing her memory/ I think we all thought about it/" [IS: 436-439]. It is not clear whom Stephen was including in his use of "we". In response to a question about it, David acknowledged that he knew that Margaret was seen for testing in a clinic for Alzheimer disease, but qualified his answer: "I don't remember/..if before they went out I knew/ or if I found out afterwards/" [ID: 172]. He described his response to that information, after explaining that his knowledge of Alzheimer's was basically what he heard in the media: "I guess it surprised me somewhat, because you sort of imagine that ha- that sort of

situation happening to an older person// I don't see my parents as being- as being that old/" [ID: 227-230]. For David, there were some parallels between his mother's problems and the problems that he associated with Alzheimer's:

"Alzheimer's...for myself / is a- is..I imagine is being...poor memory/ particularly poor..short-term memory/ and uh and s- sort of just..**lost// and..uh..I kinda see the similarities in my mom just gets lost in what she's saying/ you know/ she'll go along and - she won't have a totally **blank look/ but you can tell she's trying to think of the word and it's not there//"

[ID: 74-82]

Although David described using the similarity to Alzheimer's to explain his mother's diagnosis to his friends, he also differentiated it from Alzheimer's: "I don't know if it's fair to say/ that- that one is..is..less in**tense than the other/ but I would personally think that what my mom is...having to deal with/ is not as bad as having to deal with Alzheimer's/" [ID: 89-91].

While Stephen's use of "we" may or may not have included David, it probably did include his parents. Both John and Margaret talked about Margaret's distress at learning that she had been referred to a clinic for Alzheimer disease. Margaret, sighing, commented: "I - I was dead against it/" [IM: 132], while John explained that, when they learned which clinic was calling to set up an appointment: "that threw Margaret for a real loop/" [IJ: 369] He explained further: "just as they were saying {[heh-heh] on the radio} at noon today/ there **is a kind of stigma attached/ to..to uh/..not..legitimate/ but I mean tha- there just **is/ in people's minds/" [IJ: 375-379]. His comments about the stigma of Alzheimer's, coupled with his strategy of proactively telling people of his wife's diagnosis, suggest that John did not acknowledge any public stigma surrounding primary progressive aphasia.

Despite being given a diagnosis of primary progressive aphasia, for Margaret and John at least, the investigations themselves raised the possibility of Alzheimer's disease, with ongoing uncertainty about how, if at all, her diagnosis is related to Alzheimer's. In John's understanding:

"it was just clear/ that the thing is similar enough to Alzheimer's,
that..obviously that the..the much larger disease in numbers/
is going to have the..the thing named after it//
I- I'm sure that the two were not distinguished at **all/
more than fifteen or twenty years ago// um...yeah, it..it uh –
that again was part of the overall shock/ of finding out what this **was//"
[IJ: 380-388]

Uncertainty about the relationship of the two disorders manifested also as uncertainty about the future, captured both in John's words and in his uncharacteristically hesitant manner:

"I really don't know...how – in the long term yet/
how – ..whether it leads to Alzheimer's, or whether it- it..it you know/
whether there's a re- a co-..real connection between the two,
although they uh..are..uh/ uh..they're manifest by different uh/
..different pathology/ of the...of the brain//"
[IJ: 345-341]

For Margaret, too, the overt link to Alzheimer's raised distressing possibilities. Although she had difficulty verbally expressing her understanding of that link, she clearly conveyed her fears for herself: "I I have um..um..the..um...feeling/ that- that I'm going to get..Alzheimer's// and uh.. it's um/...um.... one- one percent/ out out of..uh..ten/ /on..on the uh/...list//"
[IM: 135-139] After trying to clarify this further with Margaret, I was still not confident of my interpretation of her understanding that ten percent of the people seen by her neurologist and diagnosed with primary progressive aphasia went on to develop Alzheimer's disease. However, the actual numbers themselves were clearly

less important than the fact of a quantifiable possibility leading to a troubling premonition.

Limited information about the nature and cause of progressive aphasia led to uncertainty in other troubling ways. Christine commented: "if I- if that started happening to me/..I don't know what I would do// um..I'm hoping it's..it's nothing hereditary,..um..{[p] you know, that would be_} that would- that would scare me very much/" [IC: 140-144]. Her comment highlights how the diagnosis itself can have unknown implications for other members of the family, leading to uncertainty about their own futures.

Uncertainty about future expectations emerged in all the Thompson family interviews. Although all family members expressed their understanding that Margaret's problems would get worse, they had no clear expectation beyond the commonly held assumption that she could reach a point where she would not be able to speak at all. For John, there were already signs that more might be involved than just communication, as he expressed concern about other capabilities: "her decision-making..ability has definitely deteriorated/" [IJ: 180], an observation that may have been part of his concern about the disorder evolving into Alzheimer's. David too was aware of the progression of the disorder to the point that it affected more than his mother's verbal communication, commenting that she was also beginning to have trouble in playing the piano and in reading. However, he also was less certain than other family members in assuming that his mother would continue to decline, qualifying at one point "if it gets any worse/" [ID: 574], a qualification that allows for the possibility of a different outcome. Stephen too,

while anticipating progression, explained: "what I **don't know is how far it goes// which is what I'm concerned about/" [IS: 34-36].

In contrast to other family members who described expectations in terms of Margaret's declining abilities, Angela expressed concern about the consequences of anticipated losses. She recognized that more than her mother's speech could be affected:

"I know that in..in time, my mom may not be able to speak at all,
I know that..that it's a two way thing,
that it's not just..uh..inability to put her thoughts..into words/
or into symbols of writing/ but also to..to translate..words coming to her/
or symbols coming to her into..into thoughts/"

[IA: 127-129]

For Angela this meant that "progressively she's being cut off/ from <2> some parts of the world/" [IA: 130] with the consequence that "clearly/ she could not..take care of her..*self" [IA: 148].

Uncertainty about what to expect with primary progressive aphasia was compounded, for at least some members of the Thompson family, by uncertainty about what to do about it. John's frustration was clear, as he explained:

"when it was first diagnosed/ the first thing you want to know is/
well what can be **done about it//
um..I'd *still like to know **that, {[heh-heh-heh] the answer to *that one/}
I'd still like to know/ **what..{[dc] if anything/
..**we should be doing/ to prepare for it/"

[IJ: 116-124]

He continued to hope for a medical solution: "one **hopes that tomorrow/ or something, they will find some- not **cure/ but something that will/...at least slow down the progress/" [IJ: 279-281], drawing again on the parallel of Alzheimer's: "one was hearing/ just a few days ago/ about some new..uh discovery being made/ that they felt was uh/..very optimistic for..um..Alzheimer's patients/" [IJ: 285-289]. In the absence of

such advances for primary progressive aphasia, there is a sense of helplessness in his statement: "I *wish I knew **more// that's the *single thing I can say/" [IJ: 266-267].

Christine echoed her father's frustration in her description of learning from him about her mother's diagnosis: "I know that there was a lot of- a *lot of frustration with – when I ..when I heard that they were going through this/ but there was no real...information? like what caused it/ what you can **do/" [IC: 631-633]. She too had unanswered questions:

"I guess::..I guess I'm still kind of in the dark/
as to what..if one does have this diagnosis/
is there something that one can work on/ to improve things/
or..or to keep it from getting worse, or::_
...but ..I-I'm still a little mystified/ by the whole..the whole thing"
[IC: 160-165]

She summarized these uncertainties later in her comment: "the *main thing I would like to know, is- is if there's something I can sort of *do, to sort of *help" [IC: 749-751].

Again, the relatively sparse information about the diagnosis of primary progressive aphasia was problematic for the family, contributing to their sense of helplessness in coping with the present or planning for the future. The diagnosis itself provided little or no support in guiding them, while its uncertain relationship to Alzheimer's raised troubling questions that could not be answered.

Conversational Constructions of PPA as Diagnostic Category

In the three recorded conversations with members of the Thompson family that included both daughters and grandchildren, the predominant manifestation of Margaret's progressive aphasia that reflected family members' descriptions of it was her very limited verbal participation. This is perhaps not surprising in that these conversations included

at least six family members spanning three generations, all together for the first time in years. At times, more than one conversation was taking place simultaneously and, especially in those instances when everyone was talking together, the conversation moved rapidly with frequent changes in topic. In the remaining two conversations, both of which included only three participants, progressive aphasia emerged, both in speech patterns that had been described by family members as symptoms and, also, as something that could itself be talked about.

Speech Patterns as Symptoms and Accommodations

One of the most frequently described symptoms that her family associated with progressive aphasia was Margaret's difficulty in finding words. This problem was most evident in my conversation with her and John, as it was in this conversation that she participated most actively. The following excerpt illustrates clearly the problems that she experienced when contributing new information to the conversation (for numerous further examples, see Appendix F Transcript 2):

Excerpt 6.1

1. B: well/ what do you *think//
2. J: well, [M laughs]*we could sit *down/ but uh..the =*stuff=isn't*ready yet,
3. B: =o*kay,=
4. *where would you like me to *sit/ Margaret?
5. J: ==right *there//
6. B: *this one?
7. J: yeah/ ...the other *two are..where *we usually *sit,
8. B: ...now would you –
#nothing audible re why B breaks off, but it is not interruption#
9. M: {[h] *I}...I- I- I *wish to um..*be um/..um/ <10> I *wish to be uh/
10. ..*talking a-..a*bout my um/ *playing the..the pi*ano//
11. B: *oh/
12. M: uh..*and I..I..*have um/...um/..my..a- a- a*phasia ..has uh/..um <4> uh/

13. <4> my..my a*phasia *has uh/...um/
 14. J: <3> {[p] *made it..=hard for you to *read/=}
 15. M: =m::- m::- m:: = ([muh- *mordi-]) *made it/
 16. ..*hard for..for *me to uh/ ...uh..*read/
 17. J: ={[pp] *music/=

18. M:=uh/.. = *sight reading//

[C/MJB: 6.3: 1:11 – 2:30]

The word repetitions and revisions, placeholders, and long pauses in Margaret's speech all indicate her problems, not just in finding words, but also in constructing sentences; John's and my responses to those features, with neither of us moving to fill the silences until line 14, suggest that we both acknowledged them interactionally as evidence of that difficulty, constructing them as symptoms.

The excerpt also exemplifies Stephen's description of his mother's speech as sometimes "pre-meditated", which he described as easier for her than having to formulate an immediate response. However, while a pre-planned contribution was in some ways a successful accommodation to formulation difficulties, it also was problematic interactionally. Margaret's introduction of the topic in line 9, signaled as such only by her raised pitch, seemed both abrupt and oddly timed in the context of the foregoing talk as we prepared to sit down at the table for lunch. My response in line 11 comprising only the discourse marker "oh", which is frequently used to acknowledge a change in informational state (Schiffrin, 1987), signals the unexpectedness of Margaret's contribution. While it served to establish the topic (see Appendix F, Transcript 1) for ongoing discussion, it never became clear why Margaret wanted to talk about it, nor her reasons for introducing the topic at that particular time.

Other conversational features that participants associated with progressive aphasia also were exemplified in recorded conversations. The following excerpt illustrates

Margaret's tendency, reported by John, to answer forced choice questions with "yes", resulting in a conversational breakdown:

Excerpt 6.2

1. J: I'm uh..*wondering whether or *not..
2. you want to have that *butter ball *turkey that I.. won *part of last *year/
3. it's *sitting down in the {[heh-heh] *freezer//}
4. or whether you *want to make a...big la*sagna/ {[ac]as you *usually do//
5. M: ..yes//
6. J: yes/ yes =*which/ =
7. S: =la*sagna?=
8. M: yes//
9. J: never..*never give mom an =*either or {[heh-heh] situ*ation/=
10. M: =heh-heh-heh =
11. J: she'll say *yes//} [heh-heh-heh]
 <14>

[C: MJS: 1.25: 14:50-15:11]

Although John's comment indicates that he found the strategy of offering choices to be unsuccessful, the success of the strategy at other times explains why he continued to use it. The following excerpt shows that Margaret did not consistently answer "yes" to such questions; in other instances she could use one of his alternatives to formulate an answer (lines 3 and 5):

Excerpt 6.3

1. J: Margaret/ is there *anything you need to*morrow?
2. {[chewing] <2> from the *store, or can it *wait till
3. *Thursday...*morning//
4. <2>
5. M: *Thursday *morning/ I (know that) I *need um/
6. J: ..la*sagna noodles?
7. M:.[clears throat]...la*sagna noodles,...and um..cottage cheese,
8. J: yeah/ *right// mm*hm,

[C/MJAC2: 4.9: 8:19-8:48]

At other times, however, Margaret's ability to draw from foregoing comments led to more problems. The following excerpt occurred just after a rather lengthy contribution from me about offshore sailing:

Excerpt 6.4

1. J: when *we started going up/..to the *island/
2. in *nineteen seventy-*four//...*we had our- our own *boat/
3. =now *this was- =
4. M:=*we- we had a = *sailboat/
5. J: ==*not a *sail=boat/=
6. M: =uh =*no/ =no/ =
7. J: a =*power-=
8. a *stern drive// *it was an eighteen *footer//

[C/MJB: 6.24: 43:15 - 43:31]

Margaret's quick acceptance of John's correction points to her awareness of "sailboat" as the wrong word; ample evidence elsewhere of her very accurate memory for specific information suggests that this was a lexical error, triggered perhaps by the recent focus on sailing, rather than a factual one.

To summarize, the dominant manifestations of progressive aphasia that appeared in conversations with Margaret were, first, her limited participation, which can be interpreted as a symptom in the context of her family's descriptions and, second, her difficulties in formulating what she wanted to say when she did move to participate. While these features were relatively consistent across conversations, the success of strategies to accommodate to them was more variable, and her participation was significantly greater in some conversations than in others.

Talking about Primary Progressive Aphasia

Aphasia was referenced both directly and indirectly at several times in my conversation with Margaret and John. Margaret herself referred to it, both in excerpt 6.1 (line 12) above and, later in the conversation, when they were talking about her participation in a play at a local theatre (the incident under discussion here is described more fully in Appendix F, Transcript 2):

Excerpt 6.5

1. J: no/ they- they..it was *clear/ they - they *gave her..just some little *thing,
2. B: =mm*hm, =
3. M: =[heh-heh]=
4. J: that she was *'sposed to....res**pond..to/ [heh-heh] and.. she *did,
5. they *more or less *told her/ =what to *say/=
6. M: = and *I..uh..I =
7. J: {[ppp] it was uh/
8. M: was *not..*suffering from..uh..um/
9. J: a*phasia =at that time//=
10. M: =*primary = progressive a*phasia//
11. B: =mm*hm/=
12. J: = *no/ = no *this was...*well before *that//

[C/MJB: 7.5: 5:54 – 6:30]

Her overlapped expansion of John's prompt "aphasia" (line 9), giving instead the full diagnostic term, suggests the significance for her of the diagnosis itself.

In addition to these direct references to the diagnosis itself, there were also several acknowledgements of associated symptoms, sometimes in contrast to spared abilities such as memory. Margaret's good memory for specific details, particularly dates, was apparent in our interview; it also was evident in my conversation with Margaret and John on the topic of their house renovations:

Excerpt 6.6

1. M: we *did this in uh...ninety *two//
2. J: the..the up*stairs//
3. M: mm*hm/
4. J: yeah/ *I never remember/
5. ...={ [pp] all these things// }=
6. B: =you're *good at this/ = *aren't you//
7. M: [heh-heh-heh]={ [p] [heh-heh-heh] }=
8. J: =yeah/ *Margaret = re*members things like that//
9. she's got a *better *memory than *I have/ for a *lot of things//
10. { [ppp] but um/ } <2> *not unfortunately these days for **words//
11. M: { [pp] mm*hm/ }
12. B: ...but *dates/ **yeah//
13. M: { [p] yeah, [heh-heh] }

[C/MJB. 7.4: 4.49- 5.17]

Taken together, these excerpts illustrate that the topic of primary progressive aphasia and problems associated with it were openly discussed in some contexts, an observation which is consistent with John's comment that both he and Margaret recognized the advantages of acknowledging the symptoms and diagnosis to others. Nevertheless, the pattern of when these emerged as topics deserves some attention. It is not surprising that the majority of references occurred in my conversation with Margaret and John; clearly both were aware of Margaret's diagnosis as the impetus for my involvement with them. In conversations with the rest of the family, Margaret's speech problems emerged as a specific topic only once, with Stephen (discussed in the next section). It can by no means be concluded that the topic was deliberately avoided in family conversations with Margaret; with the exception of the dinner with Stephen, the circumstances of the mealtime conversations that were recorded, including Margaret's limited participation, may well have precluded either the opportunity or the impetus for such discussion. Yet, even if Margaret's symptoms and diagnosis of primary progressive

aphasia did not emerge as a topic in family conversations, they were nevertheless a significant feature of family life, which is described in the next section.

Primary Progressive Aphasia in the Family

Interview Representations

A Family of Individuals

A strong theme throughout the Thompson family interviews was that of the importance of the individuality of each of its members, reflected in several different ways. This individuality was apparent even before the interviews, during the recruitment process itself, when each family member agreed to participate at a different point in time in accordance with his or her own circumstances, rather than as the result of a family decision. During their interviews, Stephen and David in particular talked about individuality as a characteristic of their family, with Stephen explaining: "we're all different// we all got our different things// we all have different occupations/ and do- all have different interests/" [IS: 241-242] and David echoing this view: "Everybody's always been...into their own thing/" [ID: 385]. At the same time, there were allusions to the importance of family for individual members, with David commenting: "when there's a problem that they want to talk about, they come out and *talk about it/ everybody's there/ to listen/" [ID: 307-310]. John, too, suggested ways in which individual members have the support of family. In explaining that his two daughters lived in the same city, he commented: "they were not alone, they had each other/" [IJ: 951-952], a situation that he described in these terms: "it's a good arrangement/ you know/ communication wise// they

each - each part of the family has its support//” [IJ: 954-956]. Another part of that network of family support was a closeness between brothers, which David described in these terms: “it goes in phases, it comes and goes/ depending on what’s going on ea-going on in each one of our lives//” [ID. 409-411].

Three patterns emerged in the interviews with respect to Margaret’s primary progressive aphasia in the context of this interplay of individuality and family membership. The first pattern focuses on accomplishment as an expression of individuality. The second pattern captures the tension between respecting Margaret’s individuality and speaking for her. The third pattern focuses on the family response to primary progressive aphasia.

PPA: A Threat to Accomplishment, A Threat to Individuality

The importance of individual accomplishment emerged in several interviews, suggesting that it was a shared family value. For example, John spoke with evident pride of the accomplishments of his wife and each of their four children, both in the recorded interview and in other conversations. Stephen too described the accomplishments of his siblings and his parents, as in this example referring to his brother’s work: “he’s an ..*absolute **master with that” [IS: 806]. All family members spoke of Margaret’s artistic abilities, not only in terms of her accomplishment as an individual but also in terms of how her art held special meanings in the context of family life. For example, Angela commented that one of her favourite paintings was one designed to resemble a quilt, explaining that, in addition to the artistic appeal that the pattern might hold for most people, for her it was also a reminder of the patchwork quilts that her mother had made

for all the children's beds, making it particularly special: "for me it's not just noticing it/ it's – it's like it comes from..being/ from all time/" [IA:465].

In Margaret's interview, the importance of individual accomplishment was evident, but in her case it was invariably linked to references to having primary progressive aphasia. For example, in talking about learning of her diagnosis, Margaret commented: "and uh...I um <2> found um/..that um it- it was uh/ ..primary..progressive aphasia// and uh <3> I um..was sorry about that// [audible sigh] I – I have a- a- a- a- PhD in uh/ ..zoology/ and uh/ <3> I – I have uh many ar- artistic talents" [IM: 62-68]. The same pattern is seen again in this quote: "it's – it's..it's a dementia of..my brain/ ..and I uh..um/ <10> I'm – I- I'm c- cooking/ and – and um..baking at..um..my best, and um/..I – I have um/ <8> I'm grinding..wheat..for the bread" [IM: 170-177]. The repeated juxtaposition of the topics of disorder and accomplishment in Margaret's interview suggests that, for her, primary progressive aphasia represented a threat to her presentation as an accomplished individual, possibly because her abilities were themselves at risk and possibly because it prevented others from seeing those abilities that remained.

Other family members, talking about changes in family life that they associated with primary progressive aphasia, also spoke of Margaret in ways that supported her presentation as an accomplished individual. In many instances, they did so by contrasting present problems, attributed to PPA, with previous abilities. John, after describing the severity of Margaret's word-finding problems, commented: "for most of her **life/ Margaret was a very articulate person/" [IJ: 101]. David talked about his mother's role in family conversations: "she was an excellent resource/ 'cause..she knew

a lot about...she knew...much about...many different topics/" [ID: 494-496]. For him, however, she no longer held this role: "{[p] now it's gone/} either there – either there's...there is no interest,...anymore, or she just can't remember/ or can't remember the terminology, and just doesn't want to get into it/" [ID: 518-519]. Stephen too alluded to this ability: "she used to talk a **lot/ when I'd ask her quest- scientific questions/ she'd tell me a lot/ and go dig out her books/ and tell me/" [IS: 59-60].

Like Margaret, Stephen juxtaposed comments about loss with references to her remaining abilities: "she plays her music on the piano, and she does her art, and uh...otherwise she's just...the same as m- the same mom I've always **had/" [IS: 55-56]. Other family members too emphasized her spared talents. For example, Christine commented that it was fortunate that her mother's art was not affected because it was something that she had "such talent and such passion for" [IC: 656]. Family members also described how, though she was unable to participate in family conversations, she nonetheless continued to participate in family life, maintaining responsibility for the cooking. When I misunderstood a comment in my interview with Margaret and explained: "I thought maybe you might be cooking together you know" [IM: 1030], Margaret replied: **John doesn't **cook/" [IM: 10310]. John later echoed this, commenting: "when it comes to inviting somebody to come for a meal, well then I figure Margaret's got to be consulted about this/ 'cause – 'cause while I may be {[heh-heh-heh] the vacuum cleaner, I'm not the food preparer}"/ [IJ: 1549-1553].

Nonetheless, despite the fact that family members continued to support and value Margaret's abilities, they too recognized the threat that progressive aphasia posed for her individuality. Stephen summarized that view in describing his concern that his mother

was no longer intending to participate in an annual art show: “she doesn’t have to impress anyone in her family/ they’re already all impressed/ but maybe she might want to impress some other people outside of the family once in a while/” [IS: 591-592].

Respecting Individuality while Speaking for Another

While all members of the family were clearly affected by Margaret’s increasing difficulty with communication, each commented that, apart from Margaret herself, it was most difficult for John. In Margaret’s words: “it’s a- a- a- affected me um <6> grossly//...and um...it- it’s uh a- af- affected..uh..m- my husband/ um <3> [.hhh] severely//” [IM: 343-346]. For John, it became necessary to speak for Margaret; as he said: “I have to do more and more/ of the interfacing with the world/” [IJ; 237]. Speaking for Margaret, in this context, meant speaking on her behalf, as he clearly respected her autonomy: “she’s always been her own person/ and has done what she wants to do” [IJ: 867-868]. In interfacing with the world, he did so as her representative, exemplified in this description of their respective roles at a sale of her art work: “she just directed people to me/ when they – wanted- and uh..that was **fine/ yeah/” [IJ: 620-621].

The different ways in which one might speak for another become clearer in considering it in the context of family communication patterns. John, like others in the family, acknowledged that he had always been more dominant in conversation, saying: “I probably always did most of the talking/ because I’m just..that kind of person/ but – I mean Margaret did a lot/ and Margaret was very articulate/” [IJ: 1418-1421]. Angela too acknowledged this pattern, citing it as one example of why she did not at first notice her mother’s word-finding difficulty: “in telephone conversations to my parents/ my dad often does just jump in/ and answer for my mom anyways, – that was a pattern like long

established/" [IA: 80-81]. However, as David pointed out, his mother did not always accept his father's speaking for her: "she'd be pretty aggressive, if she needed to be, yeah/" [ID: 1074].

Margaret's increasing difficulty with communication presented new challenges in that long established pattern. Angela summarized those challenges, at the same time drawing attention to how, in her view, they changed with her mother's increasing difficulty in communication. Speaking of her father's tendency to answer for her mother, she commented:

"early on with this/ I think it bugged her –
it seemed like it bugged her even more/ because..he was doing this/
and::..uh..and she couldn't..**trump him/ she couldn't say/
{ [heh-heh-heh] you got it wrong/ I'll do it for myself sort of thing/}
she couldn't trump him/ because...it was too difficult to jump **in/"

[IA: 370-375]

Over time, however, she saw changes in that pattern:

"um..now..now I th- I think my mom just has –
just has more..peace with – or just more acceptance/
that – that because she **can't..often/
in dealings with other people/ re- respond/
um..that..having my dad...jump in there/
is...probably the...{ [heh-heh] the most expeditious way to **go/}

[IA: 402-405]

Family members were sensitive to the difference between hearing Margaret's own voice and hearing it through another, exemplified in Stephen's comment: "she said – well actually my father said *for her/ but <2> ..uh..the understanding is/ [remainder omitted]" [IS: 581]. John too recognized a difference between speaking for Margaret when she could freely contradict him and speaking on her behalf because of her difficulty in speaking for herself. He captured this difference in these words: "I still do most of the talking/ but Margaret does..much less/ in fact than she was able to do/" [IJ: 1425-1427].

His choice of words suggests, not that she was talking less in public but, rather, that her silence was now more often due to inability, an inability that precluded choice. His strategy of ensuring that others knew about Margaret's diagnosis was possibly to mitigate any discomfort that might be associated with his tendency to speak for her; in John's words: "as long as people know/ what the reason is, ..then it doesn't - ..you know, it - you don't feel awkward about it//" [IJ: 1431-1432].

Another problem associated with Margaret's progressive aphasia was that even her family had increasing difficulty in knowing what she wanted. As John explained in describing his own communication with Margaret: "she is not **able to say/ what she means//" [IJ:1113]. Angela was more explicit in talking about the implications of this problem for family members speaking on Margaret's behalf:

"if she's starting to lose the ability to..to communicate/
we have to ask her **now/ what does she want to happen/
if that..if..if dad..passes away, or is not able to..take care of her..effectively//
um..what does..what does she want/ what can she can tell us about that **now/
because there ..could be a time/ when she can't..tell us **anything//"

[IA: 152-156]

If Margaret's family was to speak on her behalf while respecting her individuality, both in the present and in some projected future, they clearly recognized both the need for and the difficulty in knowing what she would want.

A Family Response to Primary Progressive Aphasia

Margaret's diagnosis of primary progressive aphasia was an event that represented, in Angela's words: "something to deal with at progressive levels/..in..in our life as family/" [IA: 104]. It triggered a coming together of the whole family, both geographically and in other ways, as Angela explained:

“Christine’s the one that...we see the most of, that *I see the most of,
um..so, <2> certainly..the two of us decided, yeah/ we’ll come/
we’ll come together/
um <2> that – there could be a sense of..um..everybody::coming together/
like..my brothers and my parents/ and ourselves/”

[IA: 221-227]

Her comment, in addition to explaining how the family as a whole was coming together, implicitly acknowledged internal family connectedness of brothers, sisters, and parents, echoing John’s earlier comment about each part of the family having its support. David too alluded to this coming together of the whole family:

“so it’s gonna be the first time/ in quite some time/
that..all four of the ..siblings have been together/
uh..so I’m sure there will be some...interesting conversations there/
not only..with the whole family/ but also between..my various siblings/
because you know/ there are definitely things to discuss/”

[ID: 559-562]

While looking forward to the opportunity to discuss issues with all of his siblings, he was also aware that his sisters were coming to speak with their mother while “she- while she still can/” [ID: 573].

In talking about the family coming together, Angela alluded in several different ways to overcoming distance. She described how, in a phone call with David, she became aware of the impact of his mother’s disorder on him, going on to say: “he’s right *here, whereas I’m *way off *there, [omitted] so I really **heard in his..his voice/ that sense of/ {[dc] I *see it *day after *day...Angela/} I..I **know::/ something that...*others ..*don’t..fully *grasp yet/” [IA: 268-273]. Angela and Christine, though living at a distance, both recognized the need to support their brothers, especially David, who was “right here”.

Distance, however, was not just geographical. It also was subtly associated with the family pattern of respecting each person's privacy, a quality that David described as follows: "people just uh..respect each other's space/" [ID: 304]. For Angela, her mother's diagnosis prompted a re-examination of that quality: "I think I just had kind of an emotional uh/...um..*sense of <2> of um <3> the..maybe the distance? the distance/ between myself and my..parents/ that I've never..bothered to <3> try to bridge_ um..didn't seem like..a big concern, or high priority" [IA: 161-164]. She described her mother as "somebody who didn't..talk about..uh/ what she was thinking or feeling/ you more had to infer/" [IA: 610-611], a characteristic that she thought would only get worse with the progression of PPA. At the same time, learning of the diagnosis gave her the opportunity to address that distance, leading her to comment: "[h, heh-heh-heh] so it's *good in a way, that's good in a way, }..I mean *lots of people don't get that/ uh..that..chance to really think about..*think about..that// you know/..think about..**loss/" [IA: 184-186]. Angela's pitch change and slight laughter, together with several qualifying comments not quoted here, tempered her attribution of "good" to a disorder that is most often described in wholly negative terms.

Conversational Constructions

The themes that emerged in the interviews with Thompson family members highlighted the challenges that they confronted in coping with Margaret's progressive aphasia. Analysis of participants' conversations together, framed in the context of those themes, brings insight into how those challenges were constructed and negotiated in everyday family life. These include supporting Margaret's accomplishments, speaking on her behalf, and, finally, overcoming distance by reconnecting as a family.

Supporting Accomplishment

While in family interviews, all participants described Margaret as accomplished in many areas, in their mealtime conversations it was, not surprisingly, her cooking that was most often acknowledged. In some cases, acknowledgement was formally constructed as thanks and appreciation for the meal, as in the following example:

Excerpt 6.7

1. A: it's *yummy eh Geoff?
 2. J: =it's *all yummy// =
 3. F: =[~] *mm::} =
 4. C: =[~]mm::...}=[~]mm::}=
 5. A: say *thank you grandma *Margaret,
- [C/MJAC1.4.26: 34:36-34:45]

The value of Margaret's cooking, however, extended beyond the present of any particular meal. Good, healthy food was also constructed in conversation as a shared family value that united them over time:

Excerpt 6.8

1. D: well *you guys were always *good at that though/
2. J: =well *you were all- =
3. D: =I re*member you =guys always *bought – bought *bulk,
4. and *spent =some *time = you know/
5. J: =that's *right/=
6. D: *getting it all put a*way properly, and pre*pared,
7. and the *square *hamburger patties, {[p] and the *cookie *trays,}
8. D: it was all *good/ =that made *sense/=
9. M: =[heh-heh-heh] =
10. C: *I thought that *hamburgers were =sup*posed to be square/=
11. M: = [heh-heh-heh] =
12. C: =*I thought the *restaurants were doing them all wrong/=
13. M: = [heh-heh-heh] =
14. J: =well, eventually Wendy -=
15. C: =like *where's the *corners/ =
16. J: {[~] eventually *Wendy's got the i*dea//}
17. C: =*why are they cutting off the *corners//=

18. J: = [heh-heh-heh] =
 19. D: *saving *beef//
 20. J: [heh-heh]

[C/MJACD.3.27: 27:48-28:15]

David's recollection here served both to reconnect the family through the shared joke of square hamburger patties and also to acknowledge his parents as good providers. This acknowledgement also appeared with reference to bread-making, a topic that appeared in several of the recorded conversations.

Excerpt 6.9

1. A: *we eat *lots of bread in our house/
 2. J: it's *funny/ when it's *just *mum and I/
 3. ..a *loaf of this *bread/ .will *normally *last us a *week//
 4. A: *yeah but you're =(it's *totally *different)=
 5. J: =because *mum = only dr- eats it/
 6. the day she *makes it,
 7. ..and uh..*I only have *two pieces/.. =the *other days//=
 8. D: =yeah but re*mem=ber back? =
 9. do you re*member the reason you guys *bought that bread machine?
 10. =it's *cause you had {[dc] *four *hungry **kids/} =
 11. J =is that we had *four .. **kids/ =
 12. M: =[heh-heh-heh]=
 13. J: =that's *right// =
 14. D: =and (*somewhere) about *seven loaves a *week/ =
 15. J: =and *mum used to make *eight loaves a *week/ =
 16. D: =yeah/=
 17. J: =yeah/ = yeah/ about *seven or eight loaves =a *week// =
 18. D: = {[p] I re*=member that//}
 [C/MJACD.3.11: 6:39 -7:10]

The overlapped similarity of the contributions between John and David in lines 9 and 11 and again in lines 14 and 15 constructed the importance of bread-making as a feature of family life; remembering it together also served to reconnect the family as a unit, with Margaret's participation marked by her laughter in line 12.

While David's comments marked good food as a family value, his reference to both parents ("you guys" in both excerpts) constructed the parental dyad as a sub-unit with shared responsibility in providing that food, without differentiating Margaret's and John's respective contributions. Their joint involvement was evident throughout the recorded conversations, as John consulted with Margaret about meal-planning, grocery shopping, etc. It was John who acknowledged Margaret specifically as the bread-maker, for example, both in line 15 above, and in the following:

Excerpt 6.10

1. J: but for *sure/...*grandma's *bread is not gonna *hurt these *kids a- at all//
2. A: =*no/..it's *very *good// =
3. J: =it's [heh-heh-heh] =
4. C: {[pp] no/..no/}
5. A: {[p] very nu*tritious//}
 {[sound of people eating] <11>}
6. M: um...*Jesse asked me.. for that uh...*recipe//
7. A: uh-*huh?
8. J: mm*hmm/,{[p] yeah//}
9. <4> I *typed it up/ so I *have it on the com*puter now/
10. J: if you're *ever =*interested= in it/
11. A: =uh-huh, =
12. J: I can *send you a *copy of it//

[C/MJAC2:5.20: 16:09-16:50]

This acknowledgement offered Margaret an opportunity to present herself as accomplished bread-maker, acknowledged by people outside the family through the request for a recipe. Her comment in line 6 is particularly significant in that it represents one of very few instances in several hours of conversation with her family in which she initiated a topic shift. In my conversation with John and Margaret, I too contributed to the conversational construction of Margaret as expert bread-maker:

Excerpt 6.11

1. B: have you *always made your own *bread Margaret?

2. M: yes// I uh..I've..*done it since um..*nineteen *eighty//
3. B: hmm//
4. <3>
5. B: and did you *always grind your own *flour?
6. M: yes// [heh-heh-heh]

[C/MJB 6.12: 23:01-23:35]

The conversational construction of Margaret's role as cook, together with the importance of that role for her family, provided a way both of acknowledging its significance for her family and of supporting her presentation as an accomplished individual. The emphasis on the continuity of that role over time, constructed in conversation as unchanging into the present, served to mitigate the threat posed by progressive aphasia to Margaret's individuality and to her role in family life.

The Complexities of Speaking for Another

Speaking for oneself, both literally and metaphorically, is strongly associated with representations of individuality, including individual autonomy. In models of conversation as a collaborative achievement, the extent to which any participant actually speaks for him or herself is interestingly problematic from a theoretical perspective. However, when complicated by a condition such as progressive aphasia that overtly compromises the participant's ability to speak, the same question is more than theoretically problematic; it is also, as comments from the Thompson family interviews have shown, deeply troubling. The problems associated with progressive aphasia can to some extent be mitigated by supportive conversation partners who can expand and interpret the partial contributions of the person with the disorder. But to what extent does such support risk dominating that person's voice, compromising her individuality and autonomy, both of which are highly valued particularly in the Thompson family?

Analysis of the family interviews revealed the family's sensitivity to this dilemma; analysis of their conversations sheds further light on how they worked to come to terms with it.

Reconsideration of an excerpt discussed earlier illustrates some of the ways in which John worked to support Margaret in the face of her verbal formulation difficulties. For this analysis, however, it is reconfigured slightly to emphasize the phenomenon of silence during this stretch of conversation:

Excerpt 6.12

1. M: {[h] *I}...I- I- I *wish to um..*be um/..um/
2. <10>
3. I *wish to be uh/ *talking a-...a*bout my um/ *playing the..the pi*ano//
4. B: *oh/
- 5.. M: uh..*and I..I..*have um/...um/..my..a- a- a*phasia ..has uh/..um
6. <4>
7. uh/
8. <4>
9. my..my a*phasia *has uh/...um/
10. <3>
11. J: {[p] *made it..=hard for you to *read/=}
12. M: =m:::- m:::- m::: = ([muh- *mordi-]) *made it/
13. ..*hard for..for *me to uh/ ...uh..*read/
14. J: = {[pp] *music/=
15. M: =uh/.. = *sight reading//

[C/MJB: 6.3: 1:11 – 2:30]

There are several interactional features here that point to John's efforts to support Margaret in talking about something that was clearly important to her. One strategy that he used was to allow silence, acknowledging her place-holders (e.g., "um") as a bid for more time to formulate her contribution. Placing significant pauses on a separate line in transcription reminds us that, for the interactants in real time, silence represents an opportunity for someone else to take over the floor, and yet here, neither John nor I

moved to end the pauses, lasting as long as ten seconds, in lines 2, 6, and 8. Margaret's turn in line 9, essentially repeating line 5, contributed no new information, prompting John to move to a different supportive strategy as he ended the next pause by taking over the floor. Both in speaking quietly and also in using the pronoun "you", he constructed this contribution as a prompt for Margaret, rather than as an effort to take over explaining for her. Margaret's incorporation of his comment into her next turn acknowledged his turn as a prompt. The construction of a turn as prompt continued in line 14, with John speaking even more quietly. This time, however, Margaret chose not to incorporate it into her turn, but rather to specify it with her own completion, thereby reaffirming the individuality of her own voice in speaking for herself. Throughout this excerpt, John's strategies and Margaret's responses to them constructed an interaction in which, in speaking for Margaret, John was supporting her in formulating what she wanted to say.

Other ways of speaking for Margaret also emerged in family conversations, with different implications for her autonomy and her individual voice. When Stephen was having dinner with his parents, John told him that Margaret was not going to participate in a local event for artists in which she had routinely participated in the past. That announcement led to this exchange:

Excerpt 6.13

1. J: which *Margaret isn't par*ticipating in this year/
2. S: ==you're *not?
3. J: ==and we want to *go to/
4. M: ==*hmm mm/=
5. J: =no// =
6. S: no?
7. J: no//
8. S: *taking a *break?
9. <2>
10. M: yes/

11. J: do you have – do you *think you might want to go *back another *year?
 12. M: no/
 13. J: [heh-heh]...well-
 14. S: you should uh ..have your own *private shows then mom/
- [C/MJS: 1.22: 11:50-12:12]

After a stretch of talk about the relative benefits of private shows versus the other event, Stephen returned to the topic of Margaret's withdrawal:

Excerpt 6.14

1. S: but you're *just taking the time *off from it? or-
 2. M: um..*no//
 3. S: you *just wanna - ..that's *it//
 4. M: no um..I- I- that's *it//
 5. S: that's *it//
 6. M: mm*hm,
 7. S: *hm//
 8. J: she *doesn't feel..that she can con*tribute much/
 9. to the organi*zation of it now/ with her..*speech problems//
 10. S: and you've - ..and *that's the bottom *line/ right?
 11. M: yes//
 12. S: oh *wow/ ..*sounds like...you've *spoken//
 13. M: mm*hm,
 14. S: well, it's your de*cision/ mom,
 15. J: *mind you you *know, she's a *woman/ she can *change her *mind//
 16. S: yes, =you can *change your *mind too/=
 17. J: =[heh-heh-heh] =
 18. ...but I *think it's just as *well that she wasn't *this year//
- [C/MJS: 1.22 12:55 – 13:36]

Stephen's question in line 8 of Excerpt 6.13 introduced an explanation that constructed his mother's withdrawal both as temporary and as a voluntary break, which, after a short pause, she accepted. The explanation, however, was not allowed to stand. John's question in line 11 resulted in her acknowledging that her withdrawal was not just a break. His laugh and the discourse marker "well" in the next line suggest that this was not new information for him, constructing his original question as a challenge to her

agreement. This interpretation, however, is necessarily tentative as John did not complete his turn. Despite this exchange, at the beginning of Excerpt 6.14 Stephen again offered an account of his mother's withdrawal as temporary, suggesting his reluctance to accept it as permanent; however, the added "or" invited her to give an alternative. After her rejection of that explanation, he began to formulate a new alternative on her behalf. In abandoning that formulation to complete his turn with "that's it", not as a question, but with a clear final fall in intonation, he simultaneously acknowledged the finality of her withdrawal and allowed her the option of not offering an account for her decision. In line 4, while Margaret may have been beginning to formulate such an account, she too abandoned it, repeating instead Stephen's words and intonation to emphasize the finality of, rather than the reason for, her withdrawal.

While Stephen accepted his mother's not giving an account, John's turn in line 8 shows that, in his opinion, an account was owed. In attributing the explanation to Margaret, he spoke for her in one or both of two ways. First, he may have interpreted her abandoned utterance in line 4 as an indication that she acknowledged the need for an account, but, because of her aphasia, could not readily give an account herself. However, in contrast to his contributions in Excerpt 6.12 in which he supported her speaking, in this exchange he spoke not to prompt her but, rather, in her place, referring to her in the third person as he spoke, with normal volume, to Stephen. These interactional features suggest an alternative interpretation, that is, that he interpreted her silence as a choice not to give an account, whereas he considered that in the context of family life an account was required. In either case, in giving an account that attributed Margaret's withdrawal to the impact of progressive aphasia, John constructed it as necessary for a shared family

understanding of Margaret's circumstances, that is, an explanation that other family members had a need and a right to know.

In subsequent turns, Margaret neither endorsed nor rejected John's explanation for her decision to withdraw, nor did Stephen invite her explicitly to do so. Instead, his next turn in line 10 was ambiguous, in that "that" could be taken to refer either to his father's explanation or to the finality of his mother's withdrawal, thereby treating her silence regarding an explanation as a choice to be respected. At the same time, John's explanation was allowed to stand so that, ultimately, both Margaret's autonomous right to silence and the family's right to information, though to some extent in conflict, were supported.

Stephen's subsequent comments acknowledged Margaret's autonomy again. He acknowledged his mother's right to her decision, although his use of "well" to preface that acknowledgement suggests that he did not fully agree with that decision. John's use of humour in line 15 allowed him to take a different position to that taken in the preceding talk. In contrast to the repeated emphasis on the finality of her withdrawal, accounted for as a consequence of problems associated with progressive aphasia, he suggested the possibility of it being temporary after all. Even though this move was constructed as humour, it served to some extent to mitigate the threat of progressive aphasia implicit in his account of her decision, a mitigation that was extended in his final turn, offered in a more serious key, supporting her decision as a good one for "this year".

From an interactional perspective, the foregoing excerpts are characterized by very different types of speaking for another person, one which supports the individual's

voice, and the other which draws attention to the individual's silence. In the following excerpt, yet another type of "speaking for" is exemplified:

Excerpt 6.15

1. B: now *while those four children were *living here/
2. and *you were making eight loaves of *bread a week/
3. ..you *started doing your ph*d?
4. M: yes/ =[heh-heh-heh]=
5. J: =um- = by *that time/..you were nearly *finished//
6. M: yes//
7. J: um..because you.. *got your phd in..eighty *two?
8. M: eighty *two//
9. J: {[p] mm*hm/}
10. <4>
11. B: ..and *how many years did *that take- your ph*d?
12. M: um <3> *nearly five *years//
13. J: yeah/ um..*this was starting - *Margaret...um-
14. when *David.. was about ..*three:: years *old/
15. ...so *that would be around uh...uh::...*oh it *either..seventy *four,
16. seventy *five, ..a*round that time//
17. B: mm*hm,
18. J: uh. *Margaret de*cided to uh..-
19. M:=-...I *went - =uh..went...=went *back= to uh...
20. J: =...to *try and- = =went *back/=
21. M: um..=to uh =
22. J: =to uni = *versity//
23. M:to uh..uni*versity//
24. J: {[p] yeah but} you had *never st- *taken any
25. M:bi*ology//
26. J: ==bi*ology/ and so she de*cided to take first year bi*ology//
27. and um- {[p, ac] because her de*gree was in *physics/ and *chemistry/
28. and ..mathe*metics as *well/}
29. B: mm*hm,
30. J: .. and um..so *she- ..uh..*wondered of course/
31. as I sus*pect this would *happen to a *lot of people,
32. uh..*you know/ who've been a*way from it for a long *time,
33. you *wonder whether you can still *hack it//
34. B: mm*hm,
35. J: it took her about a *week/
36. to realize she was {[heh-heh] probably able to *hack it/
37. =much *better= than most of the *other students//}
38. M:=-mm*hm, = ==yes,
39. =[heh-heh-heh] =

40. J: =and she uh *ended up= with uh..*grades in the high *nineties//

[C/MJB: 6.14: 26:26-28:08]

The topic of this exchange was, again, Margaret's accomplishments, constructed as such by my opening reference to her activities of raising children, baking bread, and starting a Ph.D. Over the following eight lines, Margaret and John jointly constructed the narrative of her Ph.D, with John acknowledging her as a participant by addressing her in the second person. In line 13, however, he took over the narrative himself, indicated by his reference to her in the third person; this was, however, a move that Margaret resisted when she attempted to take over the floor in line 19. John respected her attempt, abandoning his own overlapping comment to support her efforts, with his contributions taken up, as in the earlier excerpt, as prompts. He then went back in line 24 to his earlier abandoned comment, now constructing it by means of the pronoun "you" as part of their joint interaction. Margaret continued to participate in that co-narration by offering her own completion in line 25. John's latched repetition of Margaret's completion allowed him in line 26 to regain control of the floor and, subsequently, of the narrative itself, as he moved again from addressing Margaret in the second person to referring to her in the third person. This time, however, Margaret did not contest his speaking for her, making no further efforts to regain the floor. For the remainder of the excerpt, John retained control of the floor, constructing a narrative that spoke of Margaret's achievements as a doctoral student. Unlike the second excerpt above, in which Margaret's neither endorsed nor rejected John's contribution, in this instance her acknowledgements in line 38 and self-deprecating laughter in line 39 both point to her agreement with John speaking for her. Having him do so, in this case, led to an enhanced presentation of her individual

accomplishments, it being more socially acceptable to praise someone else's achievements than to praise one's own.

In summary, analysis of instances of speaking for someone else reveals the complexities of such interactions, but it also draws attention to the question of *who* speaks for another. The excerpts cited above are representative of a pattern throughout the recorded conversations in which it was John, not other family members, who spoke for Margaret, highlighting their relationship as a couple of long standing. The varied circumstances and consequences of his speaking for her had implications both for Margaret's presentation as an individual and also for John's and Margaret's presentation as a couple. In some instances, John's speaking for Margaret was associated with her compromised communication abilities as when, for example, he supported her individual voice as part of the interaction. His success in doing this was to a large extent dependent on their shared history, pointing to the importance of their relationship as a couple in helping Margaret to maintain her ability to speak for herself. In other instances, such as in the narrative of the last excerpt, John's speaking for her appeared as part of a couple's negotiated joint telling of a narrative that in content highlighted Margaret's presentation as an accomplished individual, while its construction highlighted their interaction as a couple. In yet other instances, John, in speaking for Margaret, positioned her as part of a couple for which he positioned himself as spokesperson. This positioning accentuated her silence, marking the absence of her individual voice in the interaction, so that for some, though unheard, it was paradoxically maintained (cf. Stephen's comment [IS:581], p. 210).

Reconnecting

The final theme to be explored with respect to conversational constructions of family is associated with the particular circumstances of these conversations, that is, that they took place during a two-week visit when the whole family could be together for the first time in several years. As several participants commented in the interviews, the visit was prompted by Margaret's diagnosis of progressive aphasia. Although the diagnosis was represented in the interview data as an event that necessitated a family response, this was not overtly apparent in the recorded conversations. The visit also was represented in the interviews as an opportunity for the family, including Margaret, to reconnect before her progressive aphasia prevented her from taking part in such reconnections. The following excerpts illustrate the ways in which family reconnected and constructed itself through conversation, with particular focus on how, if at all, Margaret participated in that.

Not surprisingly, a significant feature of the conversation centred on reminiscence, emphasizing a shared history. In some instances, particular family relationships were constructed, as in the following example between brother and sister:

Excerpt 6.16

1. D: see *Angela, the *way I *see it, there's *nothing like coming up *here/
2. with *less rules/ *bending a few pro*pellors on boats/ to *learn//
3. ...how *things *work// [heh-heh]
4. {[h] *I even seem to remember **you/}
5. [heh-heh] putting the old *silver lining to a rock {[heh-heh] *once,}
6. =and ..*bending a *prop, =
7. A: =yeah/ and you know *why? =
8. D: =[h, f] because *you were - =
9. A: =because *I had to - =
10. D: {[h, heh-heh]because *Sally made you look for *us//}
11. A: *yes// because I *had to go get **you::/
12. {[heh-heh] because **you'd gone off with her **son//} heh-heh
13. D: {[f] and *what was wrong with *that//}

14. A: =because it was *dark// =
 15. D: =gee/ *you weren't worried,= *you weren't worried//
 16. A: well, but *I was only fif*teen//
 17. =*I didn't know (xxxx) =
 17. ={overlapping sidebar conversation between C, F, J interferes with this}=
 18. D: and *they're – all *her kids are *well into their *twenties *now//
 [C/MJACD.3.9: 5:29 - 6:03]

In his opening comment, David expressed his adult, current opinion, but that move served primarily to introduce an old dispute, initiated by his teasing accusation in lines 4 and 5. His shared recollection with Angela was itself a playful re-enactment of the original dispute, characterized by exaggerated prosody and volume, as well as their alternating justifications repeatedly introduced by “because”. It was concluded, not by resolution, but by a return to the present in David’s last comment, bracketing the dispute as an event that could be repeatedly reconstructed over time as part of a shared relationship. The lack of participation from the others, who were either engaged in their own conversation or, in Margaret’s case, silent, marked it further as particular to the two siblings.

Reminiscence, in addition to reconstructing relationships, also served to emphasize continuity over time, as in this excerpt:

Excerpt 6.17

1. A: something that's *interesting to me too/ is *going out on the rock *beach,
 2. and *seeing the same *rocks//
 3. J: in*cluding that =*pie rock/ out on *barnacle *island? =
 4. A: =yeah/ the *pie rock/ the *piece of *pie= rock//
 5. =*that's still there, and it *hasn't changed a *bit//=
 6. F: =[h, f] no *no/ it's the *piece of =cheesecake rock//}
 7. A: *okay/ it's the *piece of *cheese cake rock// {[p] what*ever//}
 8. A: and the *little *tide pools, like I *used to sit there for.. *hours/
 9 and *look in those little *tide pools, for little *crabs,
 10. J: =yeah/=
 11. A: =..by =that piece of *pie rock// [C/MJAC1.4.12: 16:08 – 16:54]

The content of Angela's comment in line 5 referred specifically to continuity in her own experience, but in the context of this conversation that experience was shared by others in her family. Continuity was constructed also as intergenerational interaction in John's naming of a particular rock, in Angela's simultaneous acknowledgement, and finally in her daughter's renaming of it for herself.

Reconnecting as a family emerged in these and other ways throughout the family conversations, but there were only two instances in which Margaret actively participated. On both occasions, her participation primarily capitalized on her good memory to contribute specific information, moving again into a role somewhat reminiscent of that described by her sons as a resource for others in family conversations.¹⁰ One of these (line 7 below) was in response to a specific question from her daughter:

Excerpt 6.18

1. A: so how *long was it that they moved *in/.. next *door//
2. J: we're *trying to re*member/ ..but she *told me/ =this *morning/=
3. A: =in the *eighties? =
4. J: that she *paid three hundred *thousand for that house//
5. C: {[\] *whoa::}
6. J: so *she got = a good *deal// =
7. M: =*eighty-*seven//=
8. A: eighty-*seven//
9. C: {[p] eighty- *seven/ =*okay//=}
10. M: =yeah/ =
11. A: o*kay/..so it was be*fore-
12. C: 'be*fore we *left//
13. A: {[p] before we *left/ for *sure//}
14. C: no- yeah *definitely/
15. 'cause I re*member {[pp] I re*member hearing it from you//}
16. J: {[p] yeah//} *you've been gone fifteen *years now//

[C/MJAC2.5.29: 28:39 29:06]

¹⁰ The link between Margaret's good memory and her role in family conversations as a resource for specific information was implicit in the juxtaposition of a discussion of her good memory (see excerpt 6.6 above) which, in our conversation, John followed by talking again about family conversations and how Margaret's knowledge of biology contributed to them.

Her question in line 16 allowed her to extend her participation, with the next several turns devoted to coming to agreement about the answer. In this exchange, it is the process of engagement of both parents and both daughters in constructing their shared history, rather than the content, that linked them as a family.

In considering these excerpts together, it is clear that, while Margaret's progressive aphasia was a catalyst for the family coming together *as* a family, it also compromised her ability to participate in the reconnecting occasioned by that coming together. In that process, Margaret's silence distanced her from the others in her family, all of whom acknowledged during their interviews the importance of finding ways to bridge that distance. These are explored further in the next section, which focuses on conversation itself.

Primary Progressive Aphasia and Conversation

Interview Representations

Characterizing Conversations

A key word associated with conversation with Margaret that emerged in several of the interviews was "difficulty". In Margaret's interview, the word appeared repeatedly, exemplified in this quote in response to a general question about conversations with others: "I am uh/..finding them uh/..quite difficult// um <3> and I..I um/ <20> {[p] I'm finding them quite difficult//"} [IA: 555-557]. John too characterized communication with Margaret in terms of difficulty, saying: "the amount of verbal communication/ that goes on between us/ has decreased/..***markedly/ as a result of

this// because it's so **difficult now//” [IJ: 1460-1463]. David, describing conversations between himself and his mother explained: “[ac, p] they don't go anywhere// they..- they=it's ju-}..it's so **painfully **difficult” [ID: 531-532]. Christine too alluded to difficulty in describing telephone conversations between just her and her mother, saying: “it's very difficult/ it's very difficult/” [IC: 297].

In contrast to these descriptions, both Stephen and Angela acknowledged Margaret's struggle in conversation, but did not describe their conversations with her as difficult. Stephen explained that if Margaret had to “just react to something/ it doesn't come across that easy for her at all//” [IS: 76] while Angela, talking about her mother's email communication, said: “you can see even in a short note/ the..the struggle to get the right word/” [IA: 427]. The difference between these two groups of descriptions, though subtle, invites exploration of the different ways in which members of the Thompson family perceive and accommodate to “difficulty”, leading also to considerations of the nature of conversation itself.

Accommodations to Difficulty and the Meaning of Conversation

All members of the Thompson family acknowledged the need to support Margaret in communication and talked about the various ways in which they did that in their own conversations with her. While some of the differences in family members' coping strategies reflected differences in their opportunities for conversation with Margaret, some also reflected differences in their interpretations of the significance of difficulty. Examination of each individual's perceptions of his or her own accommodation to changes in communication with Margaret reveals those differences and sheds light on the different meanings of conversation for family members.

John and Margaret: Frustrating communication and lost conversations.

For John and Margaret, difficulty in conversation was an ever present part of everyday life, affecting the interaction between them and their joint interaction with others. The impact of Margaret's declining communication abilities on the latter type of interaction was much less; in John's words, "there's been some..effect/ but not a great effect//." [IJ: 1380-1381] They continued to visit with friends who were aware of her disorder and, as described above, John accommodated to Margaret's declining participation by taking over more of the conversation. For Margaret, difficulty did not preclude the possibility of good conversation. In describing visits with some of those friends, she commented: "um/ <5> I have uh/...[greak] great ..conversations..with them, and al..al..al..although um/...uh..I have difficulty/ with that um/..conversations//." [IM: 713-718]. Her comments suggest the importance of conversation as a social activity, an end in itself, where difficulty could be transcended.

Nonetheless, there were some shared social activities that Margaret gave up, and John extended her withdrawal to include himself. In describing how Margaret no longer felt able to continue participating in a discussion group they had both attended, he explained: "I could have gone myself// uh..it would not have been a problem/ but I really didn't want to go without her//" [IJ: 1374-1376]. As Margaret withdrew from their activities, so too did John, rather than transforming those activities into his own.

While John acknowledged some changes in their social life together associated with Margaret's declining communication, their impact seemed relatively small compared to the impact on their communication together: "where the real problems lie/ is between Margaret and I/ we can't communicate..as **well/ as we **used to//" [IJ:

1097-1098]. John characterized these problems in several different ways. One problem for him was his difficulty in working out what Margaret was trying to tell him:

“this is ****very** frustrating for ****her**/ but it’s also very frustrating for ****me**//
because I fre- I frequently ****don’t** ****know**/ what it is//
I’ll have to just ****wait**/ I’ll say I ****don’t** know what you’re getting at/
‘cause she’ll leave out the most important word,
or she will say something/ that creates the wrong impression,
and leads me in a different direction/ than she’s trying to go//”
[IJ: 104-115]

He described specific instances, explaining how with “second guessing” and with Margaret pointing to something, he was able to work out her meaning. Nevertheless, the frustration associated with communication failures was a major theme in his interview.

A second theme that emerged in the interview with John was the loss of conversation between him and Margaret. This loss was in part mitigated by their long-standing relationship as a couple, which to some extent precluded the need for talk: “it’s now difficult enough, that – that uh/ ..we tend to ****know**::/ what’s going ****on** with each other/ and there’s lot of things/ that just don’t have to be ****said**//” [IJ: 1477-1479].

However, this theme pointed to the status of conversation as something more than just talk, echoing Margaret’s reference to “great conversation”. When I asked about conversations between him and Margaret over a meal, for example, he commented:

“not – not conversation in the ****normal** sense of the word//
yes/ there will be questions asked, and questions answered,
and- and things like that, and ..um...{[p] yeah}//
...it – there would have been far ****more**/ before this happened//
far ****far** more//”

[IJ: 1494-1500]

Good conversation was itself an accomplishment which was, for him, an important part of family life that he talked about on several occasions. In our interview, he described how, when his children’s friends used to come for dinner:

“the friends would comment to them afterwards/
 that..we had the most {[heh-heh] interesting conversations}/
 around our..uh..our dinner table//
 and it’s true/ that..we used to have very – be very wide-ranging/
 uh – and so on/ on uh..things// and that largely does not **happen anymore//
 because, it **can’t//”

[IJ: 1505-1515]

Margaret’s declining communication skills precluded such conversation between just the two of them. Although John never described this change explicitly in terms of loss, his juxtaposition of the importance of conversation and its absence clearly supports this interpretation.

David and Christine: A preference for joint interaction.

Both David and Christine described a pattern of interaction with Margaret that allowed them to take advantage of the long-standing pattern of their parents’ communication. Christine, living at a distance, spoke most often with her parents by speaker telephone: “I’m usually..mainly talking to my dad/ but my mother is listening/ so my mother’s **there/ she’ll usually say hello/ and I’ll usually say how are you/ {[p] *you know/ *fine/} [heh-heh] um..and not too much/..not too much else//” [IC: 277-287]. She described a similar pattern in face-to-face conversations during this and her most recent visit with her parents: “mostly it was just my dad, and she would occasionally put in a word, or you know/ laugh::, and whatever, but...you know//” [IC: 249-251]. She consciously tried to include her mother by supporting her passive participation, recognizing at the same time the possibility of a sense of excluding her: “I’ve tried to..you know/ address both of them/ as though I’m not just – you know/ but..{[h] but it *is something} – it *is something you *notice//” [IC: 22-264]. The alternative, however, was to risk frustration: “but um..and I don’t want to ask specific questions/ um/ <4>

things like that/" [IC: 266-268], further clarifying: "sort of like to make a choice about, or to <3> talk about something that's just gonna 'cause..you know/ frustration," [IC: 271-272]. For Christine, sparing her mother from frustration and avoiding having to cope with it herself outweighed the benefits of one-to-one conversation, so that she tended not to seek such interactions. When they did occur, such as when her mother answered the telephone and her father was not there, they were difficult: "that's even more..more complex/ because there's-..you know/ it's slow going/ uh..and that's {[p] that's kind of...belaboured I guess}"[IC: 291-193]. She described such conversations as one-sided: "when I do have any sort of conversation with my mother/ it's more one-sided/ um..you know/ I don't want to put her in an awkward position/ where she gets more frustrated/ that she can't say things/" IC: 414-417]. Her wording "any sort of conversation" itself suggests that such exchanges were not wholly satisfying as conversations.

David, living closest to his parents with more frequent opportunities for conversations with them, gave a description of his mother's participation in those conversations that echoed his sister's: "she's *there in spirit/ but she- she just has such a hard time conversing/ in an open..uh..casual dialogue with people/ that she just- ..she just stays out of it/" [ID: 472-473]. Like Christine, he was aware of the possibility of exclusion: "I feel *bad for her, because..you know of course depending on who's sitting around the table/ we're probably talking about something that she's not all that interested in/ you know? it's just- just the way it works/" [ID: 476-480]. He too, weighing inclusion against frustration, avoided risking frustration for his mother by not asking questions in dinner table discussions that he might once have asked: "I can't really ask her now/ because it- it's just almost - I feel like I'm not even being *nice/ when I *do"

[ID: 506-507]. He too did not seek out opportunities for one-to-one conversation with his mother: "there are ..*chances, but – {[ac, p] they don't *go anywhere//"} [ID: 530-531]. When they did occur he, like his father, tried to support her: "I just try to use body language_ and..and I try to...help her out if she's..trying to say something/ you know? if she's looking for a word/" [ID: 535-539]. For David, however, there were pitfalls in that approach too:

"I try not to be **too..overly helpful,
because I don't want to choose the wrong word/
you know, I frequently see my dad/ ..you know/ go down that road/
and of course *that just gets my mom even **more irritated/"
[ID: 540-542]

Instead, he elected to respect his mother's gradual withdrawal from participating in conversation: "I respect her..her space, and I respect her..will to not... be stressed out/" [ID: 545].

For both David and Christine, their mother's diagnosis of primary progressive aphasia was closely linked, possibly even causally, to her long-standing tendency to being stressed. Neither was willing to trigger even more stress for her in their efforts to accommodate to her declining communication ability. Both, instead, decided to forego opportunities for one-to-one conversations, preferring to have their conversations with her in their father's company. In those conversations, she could choose silence which, though still noticeable, was more in keeping with former family conversation patterns.

Stephen and Angela: Keeping conversations going.

In both Stephen's and Angela's descriptions of conversations with their mother, "difficulty" was characterized as Margaret's struggle, not as a characteristic of the conversations themselves. For both, the most troubling consequence of her diminishing

communication ability was not her frustration but, rather, the risk of increasing isolation. As Angela described: "progressively she's being cut **off/ from <2> from some parts of the world/" [IA: 130], with Stephen commenting: "she..must feel bad/ like she's..possibly not important/ because she can't talk/" [IS: 311]. Both acknowledged that while there were other ways in which Margaret could express herself, they were not as powerful as talk itself: in Angela's words "when it comes to everyday things/ the precision of language/ you just can't **beat it/" [IA: 134-135]. Their comments suggest that each viewed conversation as a fundamental part of relationship and so, for both, whatever conversation could be achieved took on greater value. In Stephen's words: "I've heard her say just maybe a few small..sentences to me lately/ but they meant a **lot to me/" [IS: 293-294]. Angela, after describing a particularly meaningful exchange that her mother initiated when Angela first arrived to visit, made a similar comment: "so that was..just kind of neat, because..even though...you know/ that's a very small number of **words/ but..what's be*hind it/" [IA: 313-315].

While there were similarities in the way in which Stephen and Angela talked about the importance of conversation, there were differences in how they accommodated to their mother's decreasing participation. Stephen, with many more opportunities for face-to-face conversation with his mother, described how he worked to keep her in the conversation. Like David, he acknowledged that during dinnertime conversations with his brother and father and mother, his mother participated little. However, his strategy differed from David's: "I always make sure I ask her questions/ I don't care if she answers me, and- or not// I'll a- I'll keep asking her questions/ I'll ask..just as many questions..to my mother, as I will my father/" [IS: 338-341]. For Stephen, the act of

asking itself was important: "I don't think..because she can't answer me that she doesn't – I – I don't think – I don't think that I shouldn't *talk to her" [IS: 344-345]. In asking her questions, he tried to accommodate to her difficulty in answering while still acknowledging her capabilities: "I keep the..questions – I mean..I *don't keep the questions **simple, but I make sure that they're something that can be answered easily//"
[IS: 44-45]. Stephen also developed strategies for telephone calls when his mother answered: "I'll – I'll generally just carry on a conversation/ I'll tell her about what's going on/ sometimes I'll answer my own questions/ 'cause I'm pretty sure I know what she's going to answer me/" [IS: 426-428]. Although his mother's participation appeared to be limited, Stephen's description does not emphasize one-sidedness, as Christine described. Rather, it suggests a two-party conversation in which he also took his mother's part when she could not, highlighting the act of conversation itself, rather than its substance.

Angela, in contrast to her siblings, did not focus on the challenge of sustaining conversation with her mother, but spoke instead about the importance of silence: "when someone has a condition like this/ you <2> you have to be..just be comfortable with silence/" [IA: 379-380]. Angela had had fewer opportunities than her siblings for one-to-one conversations with her mother in recent years and, as our interview took place near the beginning of her visit, was not in a position to describe how she approached such opportunities. However, in describing conversations with someone else in her experience who had difficulty in communicating, she remarked: "he also requires..effort/ to put a sentence together/ but when they're together/ **boom/ ..they all come out like that// uh..but you have to wait/ and..he has things to say/" [IA: 387-390]. Her comments

4. J: ==be*cause of- of *over-..=*over= wrong *use//
 5. A: =well - =
 6. C: =yes// =
 7. A: = um::/= a *lot of people..used to *say/..I *couldn't -
 8. ..I **couldn't..care *less/
 9. J: =oh *yes/= ==the *opposite// =
 10. C: =*then it =became/ I *could care less//=
 11. A; =and *then they started =*saying/
 12. =I *could **care *less//
 13. J: =saying I *could-= I *could *care **less//
 14. C: yes//
 15. A: ==which *means-
 16. J: ==which *means-
 17. C: ==the *opposite// =
 18. J: =the *same thing,=
 19. A: =the (*wrong?) *thing//=
 20. J: = but the *opposite// =
 21. C: yes/
 22. A: ==yeah//
 23. C: =={[p] yes//}
 24. J: {[p] yeah//}

[C/MJAC2.5.24.20:22-21:54]

The engagement of all three participants in this talk is clear, evidenced by the numerous joint constructions and overlapped talk, even though each person expressed his or her interpretation somewhat differently (e.g., lines 17-20). It may have been Angela's example, but it was one that was shared by all present (with the exception of Margaret, who remained silent through this and the remainder of the discussion about language.)

Family members also capitalized on specific language features, such as, for example, homophones and homonyms, as sources of humour and word play. David, Christine, and John most often engaged in this type of word play, which John exemplified in the following:

Excerpt 6.21

1. J: *listen/ there's *lots of li-

2. there's *lots of *goaties/ swimming around in the ..*bay out there,
 3. A: mm*hm/
 4. F: well there's only *one goatie/
 5. and *he's sitting at the table eating =*crackers//=
 6. J: =*no no no = *no/
 7. there's *lots of goaties, *swimming around in the *bay//
 8. <1.5>
 9. F: *go::_
 10. J: *ghoti//
 11. F: go =*ti::?=
 12. J: =now/ = you *gotta – you *gotta understand how it's *spelled//
 13. it's spelled *gee-
 14. {[sound of dishes moved, C or A talking to T in background]}
 15. *gee aitch, *o tee *aye//}
 16. and the *gee aitch is pro*nounced like the *gee aitch in e*nough,
 17. ...and the *o is pro*nounced like the *o in *women,
 18. ...and the *tee aye is ..pro*nounced like the *tee aye in *nation//
 19. so, "gee aitch, ..f/ ..*o,..*i, ..*tee aye/.. *sh// ..*fish//
 20. <3>
 21. A: [heh-heh] *I don't *blame you/ Frances//
 22. J: [heh-heh=-heh] =
 23. F: =*goat- *fish? =
 24. A: =it took= me *years to =under=*stand it *too/=
 25. J: =fish// =
 26. *that's what I - .that's = what I spelled *out // *fish// =
 27. A: =and I could *never re*peat it//=
 28. C: ==well
 29. when *we had **tropical fish/ that's what *dad used to *call them/
 30. the *goats//
 31. A: =mm*o:kay// =
 32. C: =he'd *always = say to me/ *have you *fed the **goats?
 33. A: =[heh-heh]*okay, } =
 34. M: =[heh-heh=- heh-heh]=
 35. C: and I re =*member once father *Thomas was over/
 36. and he said/ {[almost whispered] *you have **goats?}
 37. {[all laugh] <3>}}
 38. J: and it **all comes *out of that..*little de*vice/ *gee aitch *o tee *aye//
- [C/MJAC2.4.22: 30"27 –31:41]

Several features of this talk inform our understanding of its place in family life. First, it was constructed as part of the family's shared history of word-play, initially in Angela's unquestioning acknowledgement in line 3 and then explicitly in line 24. Second, it was constructed as a script, now to be performed for Frances, the only family member at the

table who was not familiar with it: John ignored his grand-daughter's own word play in order to keep his on the floor until she took it up, then he moved into an uninterrupted, practiced delivery. Third, Christine constructed it as part of a broader history, new not just for Frances but also, apparently, for Angela (see line 31). John's closing comment constructed the word-play itself as embedded in that family history and, therefore, also part of family connections, intergenerationally, and family reconnections, across time.

Narratives offer another opportunity for performance, in which the telling of the story is as important as the story itself. Margaret's progressive aphasia precluded her from telling her own story without considerable support (see Appendix F, Transcript 2) and, for the most part, John took over the telling of narratives common to the two of them. In the following excerpt John, who had been talking about David's independence as a young child, introduced a story about it:

Excerpt 6.22

1. J: when *he was in uh...*kindergarten/...*kindergarten? or grade *one//
 2. ...*grade **one// no *it was grade *one/ *yeah//
 3. *down at the *school here/ *just down the **road//
 4. B: mm*hm,
 5. J: *he uh/..uh..*I was on the ..*school board/ [l].. for *that *school/
 6. ..at the *time//} ..and *during the..*middle of the *year/
 7. uh..=the *board had a *party/..for the *teachers/ in the *school//=
 8. M: =[heh-heh-heh] =
 9. J: *kind of to get to *know them, ..*better,
 10. {[ac] and *so on,..=just for (*sake of it?)/}= and-
 11. M: \ =and-..and = and *he was..*asked to uh-
 12. J: no-
 13. M: to uh-
 14. <2>
 15. J: *no no *I'll- le- le- le- le- le- le- le- let..let *me/
 16. {[ac] 'cause *this thing is *inte-} his *teacher..was..uh/
 17. {[l] I- *I didn't *know her/ she..she was quite a *young woman/}
 18. and *during this *party/..*Margaret and I intro*duced ourselves to her//
- [C/MJB.7.8.12:27-13 46]

The narrative began in well-recognized style, with John providing background setting of characters and circumstances. Despite an opportunity for Margaret to contribute after line 1, she did not, leaving the opening to John, perhaps because she was not certain as to which story he was going to tell. By line 8, however, she clearly recognized it - her laughter can only be interpreted as anticipatory at that point - and by line 11 she tried to take over the floor to contribute. Her move to do so was somewhat surprising, as she very rarely moved to take the floor from John in topics that he initiated. Both the two second pause in line 14 and his response, framed as an uncharacteristically dysfluent request to be allowed to take control of the floor, acknowledged the significance of her move to participate. Line 16 offers an incomplete account of why John on this occasion resisted her efforts to do so: this was a good story. Throughout the remainder of the narrative (which, as Margaret's laughter promised and John's delivery ensured, was very funny), she made no further move to contribute except, accepting her positioning as recipient, through laughter.

Making Space

Margaret's profound language difficulty presented challenges in all conversation. In two-party talk (exemplified in this study only in my interview with her), she had opportunity to talk and the temporal disruption of conversational flow resulting from long pauses could be relatively easily accommodated. However, in two-party talk there is not only more opportunity to talk; there is also more obligation to do so, making it particularly challenging for Margaret. While it is evident from our interview together that she could participate in two-party talk, the fact that she did not choose to record any

conversations with just one other family member suggests that it was not, for her, a preferred type of interaction. Multi-party talk, in contrast, presented a completely different set of challenges. Although there was little obligation for her to speak, there was also less opportunity for her to do so. Her slowness in formulating her turns, when she did take them, disrupted the temporal organization of conversation, so that in multi-party talk her responses, when she offered them at all, often appeared after the talk had already moved on (see, for example, excerpts 6.18 and 6.19 above).

In the face of these difficulties, family members including Margaret herself looked for ways to support her as speaker in their conversations. Margaret constructed this study itself as an opportunity and a motivation for her to speak, participating most actively in the lunch-time conversation that I had with her and John. Of course, one might also attribute that more active part to her acknowledgement of her social obligations as co-host when a guest comes to visit. However, there is other evidence for the former interpretation: in the first two of the four conversations with family, Margaret made comments related to her participation in the study, marked by the presence of the audio-recorder:

Excerpt 6.23

1. <6>
 2. M: I'd *best say *something/... for *Barbara//
 3. J: *yay **Barbara//
 4. M: [heh-heh-heh]
 5. S: [heh-heh]
 6. <2>
 7. S: {[chewing] is that *it?}
 8. J: heh//
 9. S: I'll *bet she wishes she was *eating this *pork chop//
- [C/MJS.1.10: 4:34-4:59]

Margaret's comment in line 2 expressed an obligation to talk that was motivated by her agreement to participate in the study. Stephen's rejoinder in line 7 with his follow-up comment in line 9, allowing no pause for her to continue, constructed her comment as sufficient to meet that obligation. However, later in the conversation, she took advantage of his explicit invitation to talk to add more:

Excerpt 6.24

1. S: *anything *else you want to say mom? *that was a **fine *dinner//
2. do you eat *pork chops a *lot around here?
3. <2>
4. M: um:_...I *must s- say/..uh to *Barbara/
5. S: mm/
6. M: ..um..that that *I uh/
7. . <6>
8. M: ap*preciate this_
9. <3>
10. M: *micro/ [.hh,] ={[h] =*mini-} [heh-heh-heh]}=
11. J: =[hhhhh] [heh-heh-heh] =
12. well what she *used to use/ was a *big...
13. S: yeah/
14. J: *horrible thing/
 [remainder omitted]

[C/MJS:131. 21:05 – 21:47]

Margaret's choice to respond to the first of his two questions while ignoring the second constructed his whole turn as an invitation to talk with an offered topic for her to take up. Instead, she returned to the topic of the study with her reference in line 10 to the minidisk recorder that was on the table. This move, nearly twenty minutes after her initial comment, constructed her obligation as, not just to talk but, rather, to say something in particular – a delayed response to Stephen's initial question of the preceding excerpt. Her comment also served to introduce a new topic, *her* topic, as Stephen and John continued then to talk about the recording equipment that I had just begun using.

Margaret's third comment concerning the study further supports the interpretation that it offered her an opportunity to speak. It occurred at the end of the family dinner conversation where all but Stephen were present, as John moved to turn off the audio-recorder:

Excerpt 6.25

1. J: *never mind// *I'm going to turn this [recorder] *off now// *all a*greed?
2. M: um <1.5>*no//
3. J: *no/..*you don't want me to turn it *off now//
4. M: I *want to *say something//
5. J: yes//
6. M: {heh-heh}
7. <3>
8. M: I *want to..to uh... *say uh... *that's uh...um..*Barbara *Purves/
9. for *giving... me *that//
10. <1>
11. M: =*turn it *off/=
12. J: =you *want to=*thank her//
13. M: *turn it *off//
14. J: o*kay//

[C/MJACD.3.34.32:38-33:12]

One interpretation of Margaret's failure to either endorse or reject John's interpretation of her comment in line 8 is that, in this instance, the act of her speaking was as central to her turn as the meaning itself.

In addition to illustrating how the study provided a context for Margaret's talk, the foregoing examples also illustrate how family members constructed opportunities for her to participate through explicit questions, which could be taken up as invitations to talk. Such moves were not necessarily successful:

Excerpt 6.26

1. S: so *what are you gonna do when you're up at the *cabin mum?
2. ..the *usual?
3. J: ..*oh she's gonna *slave over a hot *stove,

4. M: [heh-heh-heh]
5. S: *I don't *think so/ *right?
6. <6>

[C/MJS.1.8. 3:15 – 3:34]

or they met with limited success:

Excerpt 6.27

1. A: *that's very *good// do you usually *make it this way mom?
2. =in to=*mato sauce?
3. M: =no// =
4. J: no//
5. A: do you *usually put *onions and stuff?..or_
6. J: {[p] *often puts in *lemon juice//}
7. <3>

[C/MJAC1.4.5: 3:35 - 4:32]

In both instances, John's responses may have served to maintain the flow of conversation, but they failed to acknowledge Stephen's and Marion's questions as invitations to engage Margaret in conversation. In both instances, Margaret accepted his answer as sufficient, choosing not to take up the invitation for talk herself. In other instances, however, she did take up the implied invitation:

Excerpt 6.28

1. B: {[h] is *this your home*made bread Margaret//}
2. J: =yes//=
3. M: =yes//=
4. B: ==this is- *this is the one you *grind your own *flour =for// =
5. J: =yup, =
6. B: it's de=*li = cious//
7. M: =yup, =
8. ..I..I *put um..*flax seed in it//

[C/MJB.6.9: 15:16 - 15:27]

Excerpt 6.28, in addition to illustrating a strategy of explicit questions as a way of making space for Margaret in the conversation, suggests that topic itself influenced her

participation. Cooking provided Margaret with not only a central role in family life but also a basis for her participation in conversation (see Appendix F Transcript 3 for omitted turns):

Excerpt 6.29

1. <3>
 2. J: =**very nice *person {[p]too}//=
 3. M: =(x are- are um) = I- I uh..*made these um..*fruit leathers//
 4. B: {[\} *oh:: *okay/..*how do you do *those//...do you have a..
 5. M: {[f] um_ }
 6. B: {[p,ac] do you *have to =take -=
 7. M: =de - =de*hydrate it//
 8. J: we *have a de*hydrator//
 9. B: *oh//
 10. M: ==yeah//
 - [after several turns between J and me, M again takes part]
 29. J: yeah/ just- just- just *take it/ *peel one *off, .. and um
 30. B: *thank you// =*that's= a *great way to get your *fruit//
 31. M: = that - =
 32. *this is um.. uh *apple/ ..uh..*plum and *apple//
 33. B: mm*hm,
 34. J: they *all have some *apple in them/ ..it pro*vides a good *base//
 35. but *mostly they have *other fruits/ to pro*vide a bit more *flavour//
 36. B: that's *very *good/...that's *very good//
 37. {[sound of people eating]<8>}
 38. B: the *plum really -
 39. M: ..mm*hm,
 40. <3>
 41. I *have um..*blackberry apple, ...from my *bushes//
 42. B: mm*hm,...I *wonder if people could do that..with *kiwi/..fruit//
- [C/MJB.6.18: 32:48 - 34:24]

This stretch of talk is unremarkable in itself as an example of conversation; what is noteworthy is that it was one of only very few instances in which Margaret competed for the floor to introduce a new topic. In doing so, she took advantage of the contextual support of the fruit leathers, while John and I took advantage of her topic introduction to

construct an extended framework of talk around it in which she could continue to participate.

Marking Presence

At times during the recordings, Margaret was completely silent. Although analysis of nonverbal conversational features was not undertaken in this study (primarily because of the lack of video data), the one videorecording of the Thompson family was helpful here in establishing that she was physically present during such stretches of talk. Furthermore, it showed that she followed the ongoing interaction of others during these stretches at least to the extent that she frequently looked at the speakers, but her lack of any overt verbal or gestural response positioned her more as an observer than as an active recipient of talk. At other times, however, Margaret positioned herself as an active recipient of talk, using a number of strategies including most often laughter and acknowledgement tokens.

Several studies have identified a variety of ways in which laughter can be exploited as a conversational device, both in everyday conversation among speakers with no communication difficulty (Jefferson, 1984b, 1985) and to meet the particular needs of a speaker with aphasia (Madden & Oelschlaeger, 2002). Instances of laughter accompanying speech are associated with troubles-telling, with self-deprecation, and with mitigation of negative comments; such uses have already been identified as features of the talk of several participants, including Margaret. In addition to these, however, Margaret, more than any other participant, used laughter to position herself in particular ways as a recipient of talk. Laughter is of course associated with humour and Margaret, like other participants, used it to acknowledge speakers' turns as humorous. Unlike other

participants, who, in addition to laughing, co-constructed humour in their own verbal turns, laughter emerged as Margaret's only resource in the co-construction of humour.

For Margaret, however, laughter provided a resource for other functions, one of which emerges in the following three excerpts:

Excerpt 6.30

1. C: {[h] *I saw a guy on the *street today/ wearing a *SARS mask//}
2. A: =*rea:lly? =
3. M: =[heh-heh-heh]=
4. C: {[p] yeah/} ..well he was *actually *driving/ but...
[remainder omitted]

[C/MJAC2.5.2. 1:26-1:29]

Excerpt 6.31

1. B: and it was **my first ch-
2. **first time= **I'd ever sailed =across= an *ocean, you know?
3. M: =mm*hm/ = =yes/ =
4. J: **boy/ **yeah/
5. M: =[heh-heh-heh] =
6. J: **most people do not= **do that sort of thing// [heh-heh-heh]

[C/MJB.6.23. 41:48 41.5]

Excerpt 6.32

1. S: you *know what they pay for those *high rises there?
2. just a *regular old *run of the mill *high rise looking *north?
3. down in *#name#? =in *that =area *there?
4. J: =oh yeah/= yeah/
5. S: *sixteen hundred *dollars for *one bedroom/
6. {[dc] **sixteen hundred *dollars/}
7. M: [heh-heh-heh]
8. S: =a month//=
9. M: =[heh-heh]=

[C/MJS.1.30. 18:58–19:12]

In Excerpt 6.30, the simultaneity of Margaret's laugh with Angela's exclamation points to its function as her own exclamation. In all three excerpts, her laugh takes the place of

a verbal exclamation, allowing her to co-construct, as recipient, the speaker's contribution as remarkable.

Finally, Margaret very occasionally used laughter to align herself as co-speaker with John. In addition to this use in Excerpt 6.22, line 8, discussed earlier, there was one other occurrence of this function as John was describing one of his and Margaret's favourite television programs:

Excerpt 6.33

1. J: it's *just a-.. *kind of a warm-...you *like the *people in it//
2. S: =*hmm/=
3. J: =*even = the sort of ..*semi-*crooks like..=*Greengrass=
4. M: = heh-heh-heh=
5. J: {[heh] and} *so on/ you – you *still like *them even//
6. they're..they're sort of *basically *likable *people//
7. S: it's a *good pro*duction/ eh?
8. J: *yeah//

[C/MJS.2.1.0:08 – 0:24]

As in Excerpt 6.22, Margaret's laughter in this instance pointed to her shared knowledge of the program, positioning her more as co-speaker here than as recipient.

In addition to laughter, Margaret also used minimal verbal responses not only to mark her presence but also to align herself differentially during others' talk. Jefferson (1984a) described ways in which the different acknowledgement tokens "mm hm" and "yeah" can be systematically deployed for specific purposes in conversation. She observed that, where both are used by the same speaker, "mm hm" marks the speaker's willingness to continue as recipient of talk, whereas "yeah" typically preceded the participant's self-selection as next speaker. Jefferson's analysis provided a useful framework for understanding Margaret's use of these tokens.

Margaret's use of "mm hm", in positioning her as recipient, both allowed and obligated the current speaker to continue. Typically, this was not problematic, as in the following, where Margaret's acknowledgement was overlapped by John's ongoing talk:

Excerpt 6.34

1. J: {[N] aa:h} there is *so much **work to be done up there/
2. *we should *probably [hhh]/
3. ..do *something towards [.hh]*cleaning *up certain *areas that
4. .. have *not been..*.cleaned *up for a long *time/..up there//
5. *you know what I mean/
6. M: mm=*hm/ =
7. J: =*areas =inside the *cottage where there's *stuff just sort of
8. ..*stashed a*way/
9. <2>

[C/MJS.1.9 3:34-3:55]

In this two-party talk (the only stretch, occasioned by Stephen leaving the room for a few minutes), her minimal response appeared differently:

Excerpt 6.35

1. {[sound of chewing] <15>}
2. J: so you *made {[chewing] <3>} four *loaves this afternoon?
3. M: uh..four *loaves//
4. J: mm*hm, {[chewing <2> I *heard that <2> *micronizer going,
5. *that thing *hurts my *ears/ even when I'm *off in my *study//
6. M: mm*hm/
7. <2>
8. J: it's *so bad/ [coughs] ..it's **so bad/ [clears throat]
9. {[more chewing] <20> [Stephen returns]}

[C/MJS.1.35. 24:29-25:36]

Margaret's minimal turn here, following John's final fall in intonation and followed by a two-second silence, appeared as a failure to take a turn, obliging him to continue as speaker if the talk itself was to be sustained.

Margaret also used the acknowledgement token "yes", seen in the following example which took place just prior to Excerpt 6.33 above:

Excerpt 6.36

1. J: there's a *bunch of *them on//
2. ..as *well as things like.. *knowledge network,
3. which is.. *also one of our.. *favourite -
4. S: yeah/
5. J: uh.. *channels, at *least on Saturday *night/
6. M: ==yes/
7. J: ===and uh=
8. S: =*what = do they play Saturday *night/
9. J: well uh:.*heart-=
10. M: =*heart =beat//
11. J: ==*heartbeat for *one thing/
[C/MJS.1.40.31:15-31:25]

Her use of “yes” in line 6, latched to John’s previous turn with no pause, aligned her with John as a co-speaker, a role which she more actively took over in her turn in line 10.

This differential use of acknowledgement tokens extended to another example:

Excerpt 6.37

1. J: I was uh..*saying that{[chewing] <2>}.in the *tourist industry/
2. you know, *people.. charge..fifty *bucks, .or *seventy five *bucks
3. or something to *take people on a *walk like *that/
4. along that *creek?
5. J: I've *been in *places {[heh-heh] where we've *gone on}
6. *nature hikes and *so on that weren't *nearly as interesting as *that one//
7. M: =mm*hm,=
8. A: =uh-huh, =
9. C: ==*really/
10. A: like *where/
11. J: St. *Lucia//
12. M: hmm/
13. <3>
14. A: {[pp] I *see:://}
15. <2>

[C/MJAC.4.11: 13:27-13:58]

John’s reference to both “I” and “we” in line 5 allowed Margaret the opportunity to position herself as either recipient or co-speaker. Her use of “mm hm” in line 7

positioned her as the former, a role that she maintained throughout the talk, marking John's opinion in line 11 as his, not theirs.

Margaret's use of laughter and acknowledgement tokens to position herself in different ways during others' talk allowed her to continue to participate in her family's conversations despite her compromised verbal ability. These features of talk undoubtedly contributed to her family's description of her being "there", even if not actively speaking, during their conversations. Her use of these devices during only some conversations, however, accentuated their absence during others, leading to a different kind of being "there", characterized by physical presence but interactional silence.

Summary

Analyses of interviews and conversations from members of the Thompson family, including Margaret, led to several key findings associated with the diagnosis of primary progressive aphasia and its impact on family life, particularly conversation. First, interview findings revealed how the relative obscurity of the diagnosis contributed to individuals' uncertainty about its meanings and its implications; this uncertainty was characterized in part by different interpretations of Margaret's abilities and of underlying causes. At the same time, the diagnosis legitimized concerns about Margaret's word-finding problems and prompted the family, parents and children, to address those concerns together, although here too uncertainty regarding the meanings of diagnosis complicated the family's efforts. Their coming together emerged as part of a second theme, focusing on the tensions inherent in one's status as an autonomous individual versus as a member of a family, including also meanings of distance in family life. The

theme of individuality was linked further to that of accomplishment, with progressive aphasia emerging as a threat to Margaret's presentation as an accomplished individual.

Finally, analyses shed light on meanings of the loss of conversations associated with progressive aphasia. In highlighting the various ways in which John spoke for Margaret, and in which she and other family members either accepted or contested that speaking-for, they highlighted the complexities of speaking for another. They also drew attention to the status of conversation in this family as performance, with "good" conversation as a valued activity of family life. Last, they offered insight into strategies used by each individual, including Margaret, to maintain relationship despite progressive aphasia, balancing the desire to communicate against the frustration of impairment.

Commentary

Silence was a particularly striking theme that emerged throughout both the interview and the conversational data; it is also an important feature of communicative interaction that has received considerable attention in theories of communication. Thus, it offers a productive framework for discussing the findings from the Thompson family data.

Silence in the context of interaction is a complex phenomenon, manifesting in a variety of different ways. It can occur, either volitionally or nonvolitionally, in the form of pauses or hesitations within conversation, open to a variety of interpretations, or it can occur as a communicative act itself, accompanied or unaccompanied by nonverbal signals such as gesture (Saville-Troike, 1985). In western cultures, where there is a preference for more and faster talk, conversational silence tends to be viewed in negative terms (Scollon, 1985); however, there are also positive valuations that coexist with this

negativity (Jaworski, 1993; Tannen, 1985). Tannen links these contradictory, coexistent valuations with the ambiguity of silence, suggesting that they arise from differing assumptions about what that silence signifies. She suggests that silence can be understood in terms of two major and conflicting goals of human communication: to be connected with others, and to be independent, maintaining some distance. Tannen's framing of these goals parallels the conflicting goals for individuals in family life, which was another major theme that emerged in the Thompson family interviews. In positive valuations, conversational silence can be interpreted to signify a rapport so great that no words are necessary; silence in this interpretation is not an absence, but rather a comfortable part of a longstanding interaction. It can also be viewed positively as the omission of something negative, or of respecting another's privacy. In negative valuations, it can be interpreted as an omission of something that should be said, such as a failure to return a greeting, or as a lack of rapport, a distance, in situations where, in the evaluator's view, participants should be engaged in talk.

In the Thompson family, repeated references to "good conversation" suggest that silence was not generally valued as part of interaction; rather, it represented an absence of talk. Although John acknowledged a positive value of silence in describing the rapport between him and Margaret as precluding the need for talk, it was overshadowed by his emphasis on good conversation as a significant part of family life. While Margaret shared his appreciation for good conversation, it was clear from all members of the family that she had always been a relatively silent participant in family conversations. It was also clear that, because they described her also as both articulate and knowledgeable on a wide range of topics, they interpreted her silence as a choice. While the reasons for

her choice of silence may have been unclear, making her silence ambiguous, it could at least be interpreted as volitional.

The ambiguity of silence was complicated further by the characteristics of nonfluent progressive aphasia, which disrupts the temporal regularity of everyday conversation. In conversation with Margaret, when she did make the effort to speak, word-finding difficulties and problems with sentence formulation necessitated frequent pauses, both within and between turns, creating silences in interaction that could be interpreted in different ways by her partners. As Heeschen and Schegloff (2003) point out, and as we have seen in conversations with Margaret, extended silences are jointly created as conversational partners choose not to fill them either. The advent of her struggle to talk made her silence in multi-party talk even more ambiguous, particularly as she was still part of the interaction, still listening, still being at the other end of the telephone, still being "there". The meanings of silence can be understood not just by their origins, but more importantly by what participants themselves make of them.

All members of the family constructed both negative and positive valuations of silence in their accounts and in their conversations, but the ways in which each chose to resolve those ambiguities reflect the ways in which he or she balanced the goals of seeking closeness with respecting individuality. In family conversations, moves by some participants to end Margaret's silence by inviting her to speak constructed it as negative, representing a threat to family closeness. When she did make the effort to participate, maintaining silence while she struggled to find words also constructed it as positive; silence in this context represented a strategy that encouraged closeness both by acknowledging her needs and by facilitating her participation. The more prevalent

tendency to respect her silence when she did not participate constructed it as positive, respecting her choice and at the same time sparing her the struggle to talk. At the same time, because some of these accommodations to Margaret's silence represented an extension of a long-standing pattern of family interaction, they masked the extent to which silence was necessitated by progressive aphasia. Consequently, for the adult children, meanings and impact of progressive aphasia were even more uncertain than for their parents.

For John and Margaret, their presentation as a couple both in and beyond the family, marked in part by John's tendency to speak for them both, mitigated the effect of progressive aphasia on their interactions with others. However, progressive aphasia presented formidable challenges for their interactions with each other. For them, it was a pervasive feature of everyday life that necessitated ongoing negotiation and accommodation

In the context of the negotiation of maintaining individuality and being part of a family, the circumstances in which these interviews and conversations occurred warrant particular attention. Although these recordings took place over a period of several months, the daughters' visit home, mentioned in virtually every interview and every conversation that preceded it, marked that period as a particular moment in the family's coming to terms with Margaret's diagnosis. Indeed, their coming together as a family at that time represented, not a regular occurrence in everyday life, but rather a particularly significant one that was occasioned by her diagnosis. This framing of the context of these particular family interactions as special is important to acknowledge, because it necessarily influences my interpretation of the findings. It suggests that individuals

recognized a need to construct shared understandings of the meanings of progressive aphasia for the family as a whole, but that they had not yet done so. Accordingly, it highlights the individuality of particular understandings and, at the same time, interprets participants' interactions as first steps in the construction of those family understandings.

CHAPTER SEVEN

DISCUSSION

For family members of a person with a progressive cognitive disorder, questions such as “should I say the word if she or he can’t remember it?” is one of many that they face in accommodating to changes associated with the disease. The goal of the present study was to describe how family members *do* enact the answers to such questions, and, further, to explore the meanings that those actions have for them, both as individuals and also for the family as a whole. The case studies of the Tanaka and Thompson families offer important insights into family talk in the context of disease, highlighting how family members accommodated to perceived disruption, but also how these individual accommodations were interwoven in each family’s process of coming to terms with the disease. While the findings for each family that were presented in the preceding chapters addressed the specific research questions of the study, the contribution of those findings to a broader understanding of that family process will now be discussed.

The effects of disorders such as Alzheimer’s disease and progressive aphasia on conversational abilities of individuals with these diagnoses have long been recognized, and the impact of those effects on family members is well documented (at least, in the case of Alzheimer’s disease). Findings of studies incorporating interviews, questionnaires, and/or focus groups (e.g., Orange, 1991; Powell et al., 1995; Savundranayagam et al., 2005; Small et al., 2000) have shown clearly that changes in everyday communication are a source of distress and burden for family caregivers. Studies of recorded everyday conversations between people with AD and their family

caregivers, though relatively few (Hendryx-Bedalov, 1999; Orange et al., 1996, 1998; Small et al., 2003; Small & Perry, 2005), have identified conversational behaviours that lead to communication breakdown, patterns of conversational repair, and the efficacy of different communication strategies.

The present study, in adopting the theoretical perspective of symbolic interactionism, supports and extends this research in several important ways. First, the inclusion of families with different disorders, that is, Alzheimer's disease and nonfluent progressive aphasia, led to findings that show how not only symptoms of each disorder but also cultural understandings associated with it are incorporated into meanings and accommodations to disease. Second, the analytic focus on family in the present study yielded findings that point to the special status of "family talk." Analysis of each participant's reflections on the meanings of disease and associated changes in family life, including conversation, has highlighted the intimate interweaving of conversation and relationship. The iterative process of analyzing all interviews within each family led to a deeper understanding of this finding, emphasizing how conversation contributed to the unique status of each family member's relationship with the diagnosed person and, furthermore, how changes in familiar patterns of talk were experienced with a sense of loss. Finally, it was the integration of these two methodologies (i.e., constant comparative analysis of interviews and conversation analysis of everyday family talk) that brought new insights into the nature of those changes. For example, in the Tanaka family, conversations with Rose were relatively free of breakdowns, and those that did occur were usually successfully repaired. Orange et al. (1998) reported similar findings, speculating that it may be the type and not the number of breakdowns that are distressing

for family members of people with AD. Findings from this study, drawing on both interview and conversational data, lend partial support to that speculation, but suggest that changes in the nature of conversation itself, rather than changes in the nature of conversation breakdowns, are a greater source of distress. This interpretation is consistent with Brewer's (2005) description, based on her own experience as a family member of someone with AD, portrayed through analysis of her family's conversations. Methodologically, this finding, based on the integration of interview and conversational data, exemplifies a key point of this study, that is, that the social dimensions of conversation necessitate more than a solely text-based approach to the study of any social group, such as family, of which the analyst is not a member.

In addition to extending our understanding of conversational disruption in families with progressive cognitive disorders, this study also contributes significant findings about family care. My primary interest as researcher was in how families accommodated to changes in their conversations with a member diagnosed with progressive cognitive decline, but for the family members in this study, changes in conversations were only one aspect of the changes associated with disease. For them, their changing individual and collective responsibilities for caring for that person raised issues of equally important concern. These issues relating to care emerged primarily in the interviews with members of both families, but conversational data also contributed to an understanding of how those issues were reflected in everyday talk.

Consideration of the two families together suggests some broad similarities in their process of coming to terms with disorder, but it also draws attention to differences that characterize each as a particular family. In exploring how each comes to terms with

disease, the methodological focus on family as an interactive network of individuals (versus an individual who is a family member) brings new insights to a substantial literature on family caring. The importance of studying family as a unit is well recognized (see, for example, LaRossa & Reitzes, 1993; Patterson, 1993); the combined methodologies of interview and conversation analysis in this study offer a way to accomplish this, while the findings emphasize how this approach can contribute in new ways to an understanding of family life. Ultimately, findings from both interviews and family conversation show us how the complex ways in which each family constructs itself through its interactions are uniquely its own.

Findings within each of these topics of family conversation and family caring warrant further consideration in the context of other research findings. I begin with a discussion of conversational accommodations in family talk, and then discuss findings relevant to family caring. Next, my perspective as a clinician is foregrounded as I consider clinical implications of the study. Finally, limitations of the study and directions for future research are addressed.

Conversational Accommodations in the Context of Disorder

The nature of impairments associated with both Alzheimer's disease and progressive aphasia, together with consequent changes in family life, were significant influences in the talk of both the Tanaka and the Thompson families, necessitating ongoing negotiation and accommodation in their everyday conversations.

Communication accommodation theory (Coupland, Coupland, Giles, & Henwood, 1988; Giles, Coupland, & Coupland, 1991) offers a relevant framework for discussion of these

findings, because it encompasses both a biomedical focus on cognitive changes associated with disease and an interactionist perspective exploring how social interactants construct and negotiate competence through accommodation (Hamilton, 1991). In this sociolinguistic model of conversation interaction, a speaker's production takes into consideration the productive performance of the conversation partner, the projected comprehension abilities of the partner, conversational needs, and the role relations between the partners. Conversational needs are situation-specific, in that they require interlocutors to assess constantly the extent of shared background regarding people, issues, or events, as well as situational demands and goals. The concepts of underaccommodation and overaccommodation are particularly relevant to conversations involving participants with cognitive disability. Communication underaccommodation, which can be either strategic or unintentional, occurs when one partner fails to provide sufficient support in conversation. Communication overaccommodation occurs when one participant provides more information or support than is required, resulting in communication that can be perceived by others as demeaning or patronizing (Ryan, Meredith, MacLean, & Orange, 1995). In contrast, as Ryan et al. point out, communication that successfully accommodates to individuals' specific needs and abilities empowers and supports the well-being of both interlocutors.

Hamilton (1991) suggested that communication breakdown necessitates responses to address both its linguistic and social consequences. Response strategies designed to address linguistic consequences are intended to restore interactional coherence. Drawing on Brown and Levinson's (1987) theory of politeness, Hamilton differentiated two kinds of response strategies used to address social consequences, namely those designed to

respect individuals' need for independence (negative politeness strategies) and those designed to respect their need for closeness (positive politeness strategies). Response strategies, according to Hamilton, can be situated in tridimensional space along these three axes, that is, coherence, negative politeness, and positive politeness. She cited Robin Lakoff's (1973) claim that in most informal conversations, face (i.e., politeness) takes precedence over clarity (i.e., coherence), because in these conversations, building relationship is more important than communicating ideas (Hamilton, 1991, p. 176). She drew on her conversations with Elsie, a woman with Alzheimer's disease, to illustrate how her own response strategies to problematic communication negotiated challenges to coherence, positive, and negative face.

As Hamilton pointed out, the challenge for participants in conversations with people with cognitive impairments, particularly those associated with progressive disorders where deficits fluctuate, is to find the "right" level of accommodation, as well as the "right" response strategies. Her work, like that of others (e.g., Sabat, 2001), describes these challenges from the perspective of an interlocutor meeting someone only after (and, it might be argued in many cases, because) they have developed AD. For family members, finding the "right" level of accommodation and response strategies is particularly problematic, as it is complicated by a history of well-established patterns of conversation with their relative, necessitating attention to and reevaluation of long-standing assumptions and patterns of interaction. Findings from this study offer insight into the nature of these challenges.

For the Tanaka and the Thompson families, a major challenge lay in understanding the nature of cognitive changes associated with disease, not just in the

clinical sense afforded by assessments, but translated into the everyday context of their life-world. For these families, as for many others reported in the research literature (Perry, 1994; Smith, 2000), diagnosis offered a way of making sense of behaviours that violated their expectations and conceptualizations of Rose and Margaret. The two diagnoses, however, differed in the ways that they could be incorporated into family understandings. The more common diagnosis of Alzheimer's disease, with its well established public information and support programs, is associated with relatively monolithic descriptions of behaviours and progression of symptoms; these gave family members some guidance in understanding and coping with perceived changes in Rose's behaviours. However, differences between Rose's behaviours in everyday interactions and expectations of Rose's behaviours framed by understandings of her as a person with AD were made problematic by such reification, as evidenced by, for example, Linda's confusion about why her mother could remember how to dress herself beautifully for a luncheon, but could not remember to wear the clothes that she and her daughter had selected the day before. Was this because of fluctuation in cognitive abilities? Or, was it resistance to perceived overaccommodation? Similar confusion is seen in Tom's efforts to reconcile his experiences of Rose's disordered talk with the intermittent occurrence of the "just normal day". In this context, family members' utilization of questions that ask about presumably shared knowledge but seem intended to test recollection may represent genuine attempts to ascertain, at that moment, in that conversation, the "right" level of accommodation.

In contrast, the less well-established and problematic diagnosis of primary progressive aphasia offered the Thompson family little guidance beyond affirming their

impressions of something wrong with Margaret's language and, additionally, offering an account which could legitimize changes in their interactions in their social network. While such uses of diagnoses have been identified as beneficial for families (Hanson, 1991, 1997; Robinson et al., 1998), the diagnosis of PPA was limited in the extent to which it helped family members to understand Margaret's impairments and her particular conversational needs. Because of the lack of readily accessible literature, limited representation in public discourse, and absence of specific resources such as peer support groups, family members had only their own observations as a framework for accommodations. While it can be argued that such an empirical approach may reduce stereotyping and stigmatization, it occasioned, for the Thompsons, great uncertainty as to whether their accommodations were the "right" ones. Furthermore, in contrast to the predictability and order, however illusory, in constructions of the diagnosis of AD, the diagnosis of primary progressive aphasia was associated with even greater uncertainty about expectations for future change.

Differences in the response strategies of individuals within each family highlight the ways in which their understandings of diagnosis and perceived effects of disease interacted with their attention both to conversational coherence and to conversation as relationship, the latter with its two dimensions of positive (need to be liked) and negative (respect for autonomy) face. In the Tanaka family, Tom, more frequently than any of his children, drew attention to breakdowns in coherence in his conversation with Rose, sometimes repairing her breakdowns himself (see, for example, Excerpt 5.39, line 19). This other-initiated repair violates a preference for self-correction (Schegloff, Jefferson, & Sacks, 1977) and, in the context of cognitive disability, threatens negative face by

highlighting the individual's dependence (Hamilton, 1991). At the same time, there may be greater tolerance for other-repair in intimate relationships, where it could be interpreted in terms of closeness. In any case, Tom's pattern of response strategies suggests that, for him, maintaining coherence was at least as important, if not more so, than face issues. In contrast, his children tended to seek response strategies that addressed face needs equally with, or more than, coherence. For example, Maria, in bringing closure to Rose's incoherent narrative (see Excerpt 5.43 line 201) responded to her contribution (maintaining positive face) while re-establishing coherence in the overall conversation, even if not in the narrative. By not drawing attention to the preceding incoherent talk, Maria avoided threats to Rose's negative face. Similarly, Colin's talk about dressing the baby (Excerpt 5.14) addressed coherence by giving Rose the information that she needed, while at the same time addressing positive face needs (giving a correct explanation that was owed) and negative face needs (through his use of mitigating discourse markers).

A key point here is that, for the Tanaka children, their mother's diagnosis of AD necessitated accommodations (e.g., contextualizing information to compensate for memory loss) to support coherence, but it also reduced their expectation of coherence. These expectations risked overaccommodation to the extent that they positioned Rose as more dependent on her interlocutor than she needed to be. Tom, in contrast, continued to expect coherent talk in conversations with his wife, highlighting his difficulty in coming to terms with her diagnosis. His expectation risked underaccommodation to the extent that he failed to give her the extra support that she, as someone with AD, might need, potentially leading to communication breakdowns. These differing expectations were

further complicated by Rose's apparent lack of awareness of her failure to maintain coherence. Hamilton (1991) attributed this form of unintentional underaccommodation to difficulty in taking the role of the other; Hutchinson and Jensen (1980) described it as part of the cognitive impairment of AD. For Rose's children in particular such underaccommodation necessitated response strategies that did not undermine her autonomy.

In the Thompson family, Margaret's word-finding difficulties led to numerous conversational breakdowns that necessitated response strategies from her family. Unlike Rose, Margaret may well have been able to identify the informational needs of her interlocutors but, because of her aphasia, she did not have the linguistic resources to provide them. For her, underaccommodation was not so much unintentional as it was unavoidable. Extended conversation with Margaret frequently resulted in breakdowns that could not be resolved, and instances of joint failure to work out what she wanted to say were frustrating for both her and her interlocutor (see, for example, Appendix F, Transcript 2). This of course reflects the relatively severe linguistic deficits, coupled with retained awareness of those deficits, that are associated with progressive aphasia, and it accounts in large part for individuals' tendency to use the negative politeness strategy of respecting Margaret's preference for silence. A second strategy of collaborative repair, used most often by John, addressed the need to maintain interactional coherence; at the same time, threats to negative face resulting from acknowledgement of her dependence were offset, at least in some instances, by John's efforts to prompt rather than speak for her, and by attention to the positive face needs of connectedness (see, for example,

Excerpt 6.12). At other times, however, Margaret challenged John's speaking for her, constructing it as overaccommodation that threatened negative face (see Excerpt 6.15).

Thus far, the primary focus of discussion has been on the accommodations and response strategies of Rose's and Margaret's family members, perhaps not surprisingly in view of the question that originally prompted this study. However, the findings have also highlighted the ways in which Rose and Margaret themselves accommodated to their disabilities; this interpretation is consistent with a recent shift from viewing conversational behaviours as deficits to viewing them as accommodations to underlying impairments (Müller & Guendozi, 2005; Simmons-Mackie, 1993; Simmons-Mackie & Damico, 1997). This shift in emphasis draws attention to the conversational benefits of, for example, repetitiveness in Rose's case, which allowed her to make conversational contributions that partners could build on in different ways (see Excerpts 5.29 – 5.32) or, in Margaret's case, placeholders (e.g., "um" or "uh") that allowed her to maintain the conversational floor while searching for words. These behaviours, whether conscious strategies or not, offered ways for each woman to satisfy the positive politeness need for closeness. In this view, Margaret's silence can be interpreted as a situational accommodation to conversational difficulty, a view that Simmons-Mackie (1993) proposed with reference to a participant with progressive aphasia in her study. At the same time, her use of backchanneling (e.g., "mmhm") and laughter enabled her to offset the threats to positive face associated with that silence.

While this view is attractive in directing our attention to the ways in which people with cognitive impairments use whatever resources they can to compensate for the limitations imposed by disease, it obscures other issues that are relevant in

communication accommodation theory. The conversation analyst (particularly one with a clinician's perspective) can identify how these behaviours as strategies achieve particular goals, (keeping conversation going, avoiding the stress of difficult conversation) but interview findings suggest that for familiar interlocutors with their own set of goals (for instance, planning the next vacation, catching up on recent events after an absence), they are interpreted as part of the larger problem of unsuccessful conversations. For families, conversations that might be considered successful in the context of cognitive disability may be experienced with a sense of loss in the context of long familiar roles.

Communication accommodation theory, with its attention to face issues, highlights the challenge for families when they must reconcile accommodations necessitated by cognitive changes with respect for the person's ability to maintain familiar roles. This was particularly evident in conversations of the Tanaka family, in which Rose continued to position herself in long-standing roles (e.g., grandmother) but, at times, required accounts that threatened her autonomy in those roles (see, for example, Linda's talk about risks in swimming in Excerpt 5.21; see also Excerpt 5.14). While analysis of conversations offered insight into how family members negotiated these different positionings, the discomfort in being confronted with such conflicts that they described in interviews framed these as essentially moral dilemmas that were never completely resolved. In the Thompson family, conflicts emerged primarily for Margaret's children as they sought to accommodate her preference for silence (respecting negative face) with expectations of conversation associated with their relationships with her in her role as mother (respecting positive face). In their case, however, these

competing demands did not involve threats to autonomy, constructing them more as relational than ethical conflicts.

Although both families faced competing demands when role accommodations were not congruent with other conversational accommodations necessitated by disability, the specific nature of these demands differed in the two families, in part because of the very different nature of the impairments associated with AD, which affected Rose's functional abilities as well as her communication, versus progressive aphasia, which had thus far spared Margaret's non-language functional abilities. Differences in the two families' accommodations can be illustrated in contrasting how each family negotiated competing demands through their talk about cooking, which emerged as a dominant theme in both families. The emergence of this theme is perhaps not surprising, as the importance of food and meals together in constructing family life has been well recognized (Blum-Kulka, 1997; Ochs, Pontecorvo, & Fasulo, 1996; Pontecorvo & Fasulo, 1999; see also DeVault, 1991 for extensive discussion) and both women in these families had held primary responsibility for cooking and meal preparation throughout their marriages. In the Tanaka family, even though others were taking over more of the cooking, they positioned Rose as family cook in their conversations with her. In so doing, they helped her to maintain that role even though she was no longer able to carry out the activities associated with it. In contrast, in the Thompson family, Margaret's ability to maintain both the activities and role of cooking served as a resource for coping with her diminishing ability to talk: individuals encouraged her participation in conversation by inviting talk about her cooking, drawing on the immediate context of the meal as a way to acknowledge and include her, however briefly, in their conversation.

In summary, findings from this study have identified both the challenges that families face in accommodating to the multiple demands of conversation with a member with progressive cognitive decline, and the strategies and resources that they bring to meeting these challenges. These findings have also identified the intensely personal ways in which dyadic relationships are constructed through conversation, reflected in each family member's talk about the meanings of conversation with his or her wife or mother, and about the impact of its loss. Finally, they have highlighted the centrality of conversation in family life,

Family Networks and Caring

As noted earlier, while my primary interest as researcher was on changes in family conversations associated with disease, the participants were also concerned with the broader issue of how to support one another in meeting the changing needs of the family. These concerns emerged primarily in interviews, but conversational data showed how they were reflected in everyday talk. The focus of this study on each family as an interwoven network of individuals, identified by family members themselves, afforded the opportunity to explore how each family as a unit identified and undertook responsibilities for care necessitated by a disorder of progressive cognitive decline. The inclusion of all family members yielded a perspective that differs from that seen in much of the research literature, which typically focuses on just one family caregiver.

In both families, the husband had primary responsibility for care of his wife, with all adult children involved in supporting their parents, although to different extents and in varying ways. The ways in which they interacted within each family to do so identifies that family as a unique unit, with its particular values, needs, and local circumstances

reflected and constructed through its pattern of caring. Differences in patterns of caring and support in each family highlight parameters of family care that warrant further discussion.

One striking difference between the Tanaka and the Thompson families is seen in the extent to which individual members collectively organized their efforts to meet the needs of the family in the context of each woman's disease. This difference can be explored along a number of different dimensions, which fall broadly into two categories, that is, the nature of caregiving and the interplay of individual versus family belonging.

Support, Care, and Caregiving

In both families, all family members (except Rose) acknowledged that the person most affected by the disorder, beyond the diagnosed woman herself, was her husband. Much of the family caregiving literature would position Tom and John either as "the primary caregiver" or as "caregiving husband". Yet "caregiver" was a term that emerged very infrequently in interviews with family members, referring only to Tom, and used only by his children, rather than by Tom as a self-designation; in the Thompson family interviews, John was never positioned as a caregiver. This pattern raises several interesting points for speculation. O'Connor (2005) pointed out that typically it was external influences, most often, in her study, support groups, that prompted the family members to self-identify as caregivers. In positioning Tom as "the caregiver", his children may have been adopting the dominant terminology of family caring in AD that is represented both in research and in support group literature, with which they were familiar. In the context of the interviews, however, they associated that positioning not

just with a different kind of care, but also with burden, offering a way to account for Tom's frustration that could help to maintain family solidarity.

Another possible reason contributing to Tom's positioning as caregiver in contrast to John is the difference in the kind of activities that each was undertaking on his wife's behalf. In the Thompson family, John described himself as having to interface more frequently with the world on Margaret's behalf but, as we have seen, this represented a quantitative change more than a qualitative one. The task-related takeover of everyday activities was not necessary, perhaps accounting for the absence of references to John as caregiver.¹¹ In contrast, changes in responsibility around meal planning and preparation emerged as a significant theme in the Tanaka family, both in their conversations, and in the children's interviews. The children's attention to such task-related changes may have contributed to their positioning Tom as caregiver; such changes have been associated with caregiving husbands in research findings of other studies. Russell (2001) found that, for the husbands in his study, cooking was associated with "the isolation and invisibility of care work" (p. 358). In contrast, Kirsi et al. (2004) found that for the husbands in their study, it was a source of accomplishment; nevertheless, they still saw it as part of their caregiving. Unlike those husbands, in the interview, Tom did not refer to his taking over of the cooking either as a source of strain or as a source of accomplishment; indeed, he did not refer to it at all. In conversation, however, his cooking was acknowledged as accomplishment in his family (see Excerpt 5.18). Such acknowledgement may partially

¹¹ This interpretation is further supported by a conversation that I had with John about 18 months after our initial interviews. In that conversation, he referred to himself as "caregiver". I commented on it, noting that he had never described himself in that way before. He replied that at the time of our first interview, he had not thought of himself as a caregiver. This changed, however, as Margaret's condition had worsened and he had to take over more of the household activities, including the cooking, a task he had rarely performed during his marriage.

explain why, in contrast to the husbands in Russell's study, he did not describe himself as isolated in caring for his wife, referring frequently to how supportive his children were in caring for their mother.

Clearly, differences emerged in the ways that family members construed their activities in supporting and caring for one another, with specific reference to caregiving the least dominant of all of these. Tom described his own and his children's activities as giving care to Rose; less evident but still present in his account was his acknowledgement of their support for him. Reflecting the managerial style of husbands reported elsewhere in the literature (Kirsi et al., 2004; Parsons, 1997; Russell, 2001) he described his own care in terms of taking over responsibility for Rose (see, for example, Excerpt 5.20). His acknowledgement of his children's involvement in caring for their mother may have contributed to his self-identification more as a manager than as a primary caregiver. In contrast, in the Thompson family, the concept of support was far more prevalent than care. While all family members expressed a need and will to help, there was considerable uncertainty about what kind of help was needed beyond coming together to offer what emotional support they could. Indeed, uncertainty around the diagnosis and its implications, together with Margaret's evident preservation of ability to carry out many of her usual activities may have made the notion of care problematic.

Individuality versus Family Belonging

To be a member of a family is to identify oneself both as an independent individual and as an interdependent part of that family. To the extent that these positions are mutually exclusive they can be conceptualized as endpoints of a continuum or as competing positionings that people must negotiate in their everyday interactions. The

interplay between family membership and individuality within the Tanaka and the Thompson families emerged very differently. Although each family recognized the needs both of family and of each individual, in their interviews the Tanakas emphasized the closeness of their family while the Thompsons emphasized their individuality.

It is tempting to link these different characterizations of closeness versus individuality to differences in sociocultural background and values of each family. Climo (1992) suggested that developments in postindustrial civilization have altered the economic interdependence of families, leading to greater economic independence and mobility for individuals, so that independence and separation have become accepted norms of adult child-parent relationships. He contrasted familial migrations, in which a family followed one individual's relocation, and individual migrations, in which the individual remained at a distance from family. For the Thompson family, there was a tradition of mobility, with the parents having moved across the country as young adults, and with the two daughters moving back to the city their parents had left. This move, as a sort of hybrid individual-family migration, reinforced a different set of family ties, as the daughters relocated near their maternal grandmother, maintaining close contact with her.

The closeness of the Tanaka family may have reflected the influence of Japanese Canadian *nisei* (second-generation Japanese Canadians) acknowledgement of filial obligations that, in their parents' world, tied children to parents from birth to death (Smith & Kobayashi, 2001). Although, according to Smith and Kobayashi, these values did not involve the same obligations for *sansei* (third-generation Japanese Canadians)

raised in English speaking households in non-Japanese neighbourhoods, *sansei* children nevertheless learned about them through observations of older family and friends.

The extent to which these differing sociocultural values influenced family styles of interaction for either the Thompsons or the Tanakas must remain open to speculation. At the level of a particular family, trends such as these merit comment, but they do not warrant conclusions. What these differences do facilitate, however, is attention to the different ways in which adult children, even those at a distance, can be involved in a family network of support. Climo (1992) acknowledged the importance of distant relationships in family life, noting that too often studies of family include only those individuals who have regular face-to-face contact with kin. He suggested that distance relationships are often discounted because of four unchallenged and potentially mistaken assumptions: 1) that near and distant emotional attachments are the same; 2) geographic distance reflects emotional distance; 3) only near-living children provide face-to-face services and health care; and 4) little can be done to improve distance relationships (pp. 11-15). Findings in this study are relevant to several of these assumptions. First, in their interviews the Thompson daughters acknowledged a need to support their parents and their brothers, including the need for face-to-face discussions about the kind of support that might be needed (hence their visit home). Despite their geographic distance, they saw themselves as part of a family network of support and were prepared to arrange for face-to-face contact to make that possible. However, distance also influenced and limited the ways in which they could participate in family support. As Margaret's communicative abilities declined, distance communication technologies of telephone and email became less effective, making it increasingly difficult for them to maintain their relationship with

her. These changes emphasized their distance from other family members' experience of her illness, leading one daughter to reflect herself on the complexities of the interrelationship of geographical and emotional distance.

Another way in which the dual positioning of persons as independent individuals and as family members emerged in these families was in their acknowledgement of how personal circumstances shaped the kind and amount of care that each could contribute. In the interview accounts of both sets of siblings, like many of those in studies of Matthews (2002) and Ingersoll-Dayton et al. (2003) there was an impression of equity, at least, to use Ingersoll-Dayton's differentiation, of psychological equity, with differences in types of support mitigated by personal circumstances.

The relatively equitable distribution of care across the family network described in both these studies, particularly the Tanakas, has been reported in other studies, but it is not the most commonly reported pattern (e.g., Globerman, 1994, 1996; Gubrium, 1988). One possibility for this difference is the way in which the study was constructed; as Kirsi et al. (2004) have shown, the context of the study itself can influence how participants construct their accounts. The methodological focus on the family as a unit may have emphasized the positioning of participants more as members of the family than as individuals, in part because they knew that other family members would have access to their accounts. Such contextualization may have led them to construct their own and others' contributions more in terms of family than in terms of their individual lives. While this possibility suggests that the study of a family as a unit may bias participants to describing more equitable distributions of care, it does not necessarily lead them to do so (see Perry & Olshansky, 1996). Rather, it highlights the difference between studies that

draw on the experience of family members as individuals versus those that focus on the family as a network of interacting individuals, underscoring the need for attention to both kinds of perspectives in understanding the experience of living with dementia.

Implications for Clinical Practice

This study has a number of implications that are relevant for formal care providers including, for example, clinical psychologists and psychiatrists, community health nurses, social workers, and speech language pathologists, who provide services to individuals with progressive cognitive impairment. One immediate and obvious implication arises from the acknowledgement that different types of progressive cognitive decline pose very different needs for families, necessitating specific services to address those needs. For families with progressive aphasia, neither Alzheimer's support groups nor aphasia support groups meet their needs; furthermore, services of speech-language pathologists are not readily available for individuals with progressive disorders. To date, the Internet is the most readily accessible resource for information. As diagnostic categories continue to evolve and become more established, needed services may well develop. In many ways, the need for such services is reminiscent of the needs of individuals with AD and their families in the early 1970's. At that time, the recommendation that senile dementia and Alzheimer's disease should be considered as a single category moved AD from the status of a relatively uncommon condition to a major health concern (Fox, 2000). However, services for individuals with progressive aphasia are not likely to benefit from such redefinition of diagnosis, which in the case of AD prompted the rise of the Alzheimer's Association. The diagnosis of progressive aphasia

requires an obligation on the part of policy makers and health care providers to develop support services that are specific to these families' needs. The findings of this study contribute to an understanding of those needs.

Findings from this study also have implications for services for families of people with Alzheimer's disease. Communication impairments have been identified as a major source of distress for families of people with AD, and considerable research has focused on identifying and evaluating strategies that can help conversation partners, including family members, to compensate for these impairments. To date, however, few if any studies have focused on the meanings of conversation and its breakdown for families. These are necessarily different from those of unfamiliar partners and, as the findings from this study suggest, are interwoven in the relationship that each family member has with the person with AD. This suggests that, for family members, conversational success may be evaluated very differently from approaches that have evaluated it in terms of, for example, the avoidance and management of local breakdowns (i.e., instances of specific breakdown necessitating repair to keep the conversation going). For family members, coming to terms with changes in conversation associated with AD means acknowledging the disease as part of the person and incorporating their understanding of its effects into their understanding of the person with it.

How, then, might we help family members to cope with the changes in conversations associated with disease? Killick and Allen (2001), drawing on Kitwood's work, emphasized the importance of acknowledging the primacy of person over dementia in the phrase "person with dementia". This injunction is particularly relevant for formal caregivers, who typically know the person only in the context of their dementia, and risk

stereotyping them in terms of social constructions of the disease. For family members, the task is surely different. For them, the challenge is to find ways of reconciling the person they have always known with the evolution of that person into someone with dementia. For formal care providers of services to those family members, the challenge is to help them to do that in ways that nevertheless encourage them to maintain and support the "person" part of Kitwood's formula.

While care providers may explicitly advocate such an approach, it is important to acknowledge implicit biases in encounters that occur at the intersection of family and formal services. The importance of interactions between family and formal caregivers has long been recognized, particularly with respect to the frail elderly (e.g., Brubaker, 1987). More recently, the need for family-formal carer interaction as partnerships has been explored (Nolan, Lundh, Grant, & Keady, 2003). Adams and Gardiner (2005), in a study of the conversations of health care triads, comprising persons with dementia, their informal carers, and community mental health nurses, contended that part of the responsibility of the health care professional is to serve as a role model for families in demonstrating enabling practices (i.e., practices that support the competence of the person with dementia). They supported their recommendation with examples that showed family members engaged in disabling practices. In contrast, the present study generally pointed to family members' efforts to support the competence of the affected individual in familiar roles. While this difference could be attributed to differences among families, it nevertheless invites consideration of other explanations, in particular the different contexts of conversations. The conversations in the present study occurred entirely within the domain of family life (with the obvious caveat that the audio recorder

represented a researcher, forming a different kind of triad), where family members routinely used enabling practices, acknowledging and supported their kin with AD in familiar, long-standing roles. In contrast, the triadic encounters described by Adams and Gardiner represent the intersection of family and health care representations of the person with AD. In such triadic encounters, family carers may position the person with AD in ways that they perceive to be congruent with a more powerful health care professionals' view. This may be particularly important if such positioning is perceived to be related to the need for services. While this interpretation does not negate Adams' and Gardiner's recommendations, it reframes the need for them, contextualizing the role modeling to the health care environment, while still recognizing that family members may be particularly valuable resources themselves in the identification and use of enabling strategies.

Research on intervention to help families cope with changes in conversation has shown some promise in helping them to acquire strategies that can facilitate more effective communication (Orange & Colton-Hudson, 1999; see also Byrne & Orange, 2005, for extensive review). However, the extent to which they help families accommodate to the loss of familiar conversations is less clear; findings from this study suggest that attention to the deeply personal, relational nature of family conversations could be an important component of intervention. It is possible that, in addition to identifying strategies that can help to avoid communication breakdowns, the process of focusing on compensations for impairments may itself help families to come to terms with changes associated with the disease by helping them to redefine communicative success. Framed in this way, intervention can be seen as helping families to recognize

conversational accommodation as an ongoing process, thereby encouraging them to develop their own strategies and resources as changes continue to emerge.

Limitations of the Research Study

While this study purported to analyze naturally-occurring conversations in the context of family life, there were methodological constraints that limit the extent to which that was accomplished. First, there is the obvious constraint that these conversations represent those that the two families were willing to share with me, as researcher, and you, as reader. This limits neither the implications nor relevance of the findings, but it does limit the extent to which these conversations are representative of other family interactions. A second constraint arose from the reliance on audiotaping. This choice facilitated data collection in a wider range of setting than could have been accomplished with videotaping, and it may also have led to less constrained conversations. However, there were instances in which information about nonverbal interactions would have facilitated analysis; without it, some phenomena simply could not be interpreted reliably.

Directions for Future Research

This study of family talk, including all those self-identified by the family unit *as* family, offered valuable insight into the way that family, as a network, constructed meanings around a diagnosis of progressive cognitive decline. The special nature of family talk that has been highlighted in this study warrants further exploration, especially given the relatively small number of studies that have examined conversation between even one family member and a person with cognitive decline. Studies of families

comprising similar or different networks (e.g., multigenerational families, fictive kin, etc.) would further inform our understanding of family conversations and care. Also, the focus here was on families at a particular moment in the evolution of the disorder. Clearly, an important direction for future research would be a longitudinal focus, using the same methodology, to explore how those meanings change over time.

Conclusion

The meanings that families assign to their experiences of disorders such as AD and progressive aphasia shape, and are shaped by, the talk of their everyday world. Because human beings are reflective actors, there is much to be learned about these meanings through individuals' talk about their experiences. However, the evolving personhood of the diagnosed individual is situated and negotiated in conversation, and so it is by attending to their conversations with that person that we can most clearly appreciate the dynamic ongoing process of families' efforts to come to terms with these disorders. Attention to these different kinds of talk has highlighted the deeply personal experience of changes in conversation that threaten each family member's relationship with the diagnosed person. Attention to the family as a network, engaged in everyday conversation together, has highlighted the ways in which family itself is constructed through its talk, offering insight into how it accommodates to changes necessitated by the diagnosis of one its members.

In asking questions such as "should I say the word...", family members are undoubtedly looking for information and suggestions that they may not have found themselves. That they would seek such assistance from every possible source is hardly

surprising, given the challenges that face them. Nevertheless, such questions position family members as less expert than the person they are asking. What is needed in family-formal carer partnerships is acknowledgement of the different kinds of expertise that each brings to that partnership. In a conversation with Tom, about a year after the last conversation that the family recorded for me, he told me that Rose's communication abilities had worsened, so that he was having even fewer meaningful conversations with her. Concerned about that loss, no longer able to rely on long-standing conversational patterns as constructions of love and intimacy, he had taken to expressing these by giving her a long hug at the start of every day together. Tom's description of the problem was framed in terms of his understanding of Alzheimer's disease and its implications for Rose's cognitive abilities, but his solution was framed in terms of his understanding of Rose as his wife, and in the meanings of their life-long relationship.

The goal of this study was not to answer the question "should I say the word?" Rather, the goal was to explore how family members, in the context of a disorder of progressive cognitive decline, answer that question in their everyday talk and, equally importantly, to gain insight into the meanings that those answers have for them. It is clear that analysis of everyday talk can and does reveal whether family members decide to say the word or not in particular contexts of talk; such analysis also reveals the consequences of that decision for the subsequent flow of talk. But it is equally clear that the meanings of those actions - saying the word or not - shape, and are shaped by, social dimensions of relationship that extend beyond the talk itself. Only by exploring those dimensions is it possible to understand the meanings that family members give to the question "should I say the word?" Ultimately, it is those meanings that suggest the need

to reframe the question, moving beyond the context of the immediate talk to ask: What does saying the word for someone communicate to that person, as well as to others, and what are the consequences of those actions, not just for talk, but for relationship itself?

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APPENDIX A

CONSENT FORMS AND CERTIFICATE OF APPROVAL FOR ETHICS

Consent Form for Person with AD or PA

Consent Form

Speaking of Alzheimer Disease and Related Disorders:
An Interplay of Family Voices

Principal Investigator: Barbara Purves, M.Sc., Doctoral Candidate,

Faculty Advisor: JoAnn Perry, RN, Ph.D., Assistant Professor

Purpose: The purpose of this study is to learn more about how people with Alzheimer disease or related disorders and their families adjust to any changes in conversational abilities that might be associated with the disease. You are being asked to take part in this study because you have Alzheimer disease or a related disorder.

Study Procedures: If you agree to take part in this study, Ms. Purves will review your health record at the UBC Clinic for Alzheimer Disease and Related Disorders. After that, she will visit you several times over approximately three months. These visits will take place in your own home, in the home of another family member, or in another place of your choosing. Each visit will last for one to two hours at a time that is best for you.

During the first visit with Ms. Purves, she will meet with you by yourself to ask a few questions about having Alzheimer disease or related disorder and about your conversations with other people. This will take about one hour. She will also interview each member of your family who wants to take part in the study. You will not be required to take part in those interviews. In addition, you and your family members will be asked to work out with Ms. Purves how often and when she can visit over the next three months.

At the beginning of each visit after that, Ms. Purves will make sure that you are still willing to take part in the research. She will then ask you and other family members present to go about talking with each other during whatever activities you are doing. For some of these visits, she will ask for permission to record the conversations with a video camera or a tape-recorder. Everyone who takes part in the conversation will be asked for their permission to be recorded. You and other family members will also be asked to record a few conversations when Ms. Purves is not there. She will give you the equipment to do this.

You will be given a journal in which you are invited to write down any thoughts you might have about Alzheimer disease or related disorder or about the study itself. At the

Consent: I understand that my consent in this study is entirely voluntary and that I may withdraw from the study or refuse to participate at any time without jeopardizing my access to further services from the UBC Clinic for Alzheimer Disease and Related Disorders.

I have received a copy of this consent for my own records.

I consent to participate in this study.

Participant Signature

Date

Consent to Show Videotapes for Scientific and Educational Purposes (to be completed in the course of the study)

I have had the opportunity to look at videotapes made of me in the course of the study. I consent to the showing of these videotapes for scientific and educational purposes. I understand that no additional identifying information will be given with these tapes during such exhibition.

Participant Signature

Date

Consent Form for Family Members

Consent Form

Speaking of Alzheimer Disease:
An Interplay of Family Voices

Principal Investigator: Barbara Purves, M.Sc., Doctoral Candidate

Faculty Advisor: JoAnn Perry, RN, Ph.D., Assistant Professor

Purpose: The purpose of this study is to learn more about how people with Alzheimer disease or related disorders and their families adjust to any changes in conversational abilities that might be associated with the disease. You are being asked to take part in this study because a person in your family has Alzheimer disease or a related disorder.

Study Procedures: If you agree to take part in this study, Ms. Purves will visit you several times over approximately three months. These visits will take place in your home, in the home of someone else in your family, or in another place of your choosing. Each visit will last for one to two hours at a time that is best for you.

During the first visit with Ms. Purves, she will meet with you by yourself to ask a few questions and to complete a questionnaire about having a family member with Alzheimer disease or related disorder and about your conversations with that person. This will take about one hour. She will also interview each member of your family who wants to take part in the study, including the person with the disorder. You will not be required to take part in those interviews. In addition, you and your family members will be asked to work out with Ms. Purves how often and when she can visit over the next three months.

At the beginning of each visit after that, Ms. Purves will make sure that you are still willing to take part in the research. She will then ask you and other family members present to go about talking with each other during whatever activities you are doing. For some of these visits, she will ask for permission to record the conversations with a video camera or a tape-recorder. Everyone who takes part in the conversation will be asked for their permission to be recorded. You and other family members will also be

I have received a copy of this consent for my own records.

I consent to participate in this study.

Participant Signature

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Consent to Show Videotapes for Scientific and Educational Purposes (to be completed in the course of the study)

I have had the opportunity to look at videotapes made of me in the course of the study. I consent to the showing of these videotapes for scientific and educational purposes. I understand that no additional identifying information will be given with these tapes during such exhibition.

Participant Signature

Date

APPENDIX B

INTERVIEW GUIDE

The following questions form an interview guide for semi-structured interviews with participants.

For establishing context and for exploring understanding of diagnosis:

Tell me about (your) / (family member with AD/PA)'s diagnosis.

Prompt questions: What diagnosis does the person / you have? What do you think that means?

Tell me about the events that led up to (you) / (family member with AD) being given that diagnosis.

Prompt question: Did you or someone else in your family notice something wrong? What happened then?

Tell me about your relationship with other family members.

How has (your) / (family member with AD/PA)'s being diagnosed affected you and your family life?

For exploring perceived changes in conversation interaction:

How has it affected your conversations with that person / other members of your family?

Prompt question (for family members of person with AD/PA): Given _'s diagnosis, do you find yourself questioning what s/he says?

APPENDIX C

SCHEDULE OF DATA COLLECTION

*Interview Data***Interview 1: Thompson Family**

Participant	Date	Setting
Margaret (PA)	Jan. 6/03	Thompson home
John (Husband)	Jan. 6/03	Thompson home
*Angela (Daughter)	Apr. 29/03	Thompson home
Christine (Daughter)	Apr. 29/03	Thompson home
Stephen (Son)	Mar. 11/03	Thompson home
David (Son)	Mar. 10/03	My office

Interview 1: Tanaka Family

Participant	Date	Setting
Rose (AD)	May 22/03	Tanaka home
Tom (Husband)	May 22/03	Tanaka home
*Linda (Daughter)	May 22/03	Linda's office
Maria (Daughter)	Apr. 24/03	Maria's office
Colin (Son)	June 6/03	Linda's office

*Children are listed in birth order in this table; all subsequent tables are in chronological order of event.

Interview 2: Thompson Family

Participant	Date	Setting
Margaret (PA)	Aug. 20/04	Thompson home
John	Aug. 20/04	Thompson home
Angela	Aug. 20/04	Telephone
Christine	Aug. 21/04	Telephone
Stephen	Aug. 24/04	Stephen's home
David	Oct. 19/04	David's home

Interview 2: Tanaka Family

Participant	Date	Setting
Rose (AD)	Oct. 24/04	Tanaka home
Tom	Oct. 24/04	Tanaka home
Maria	Oct. 29/04	Coffee shop
Linda	Oct. 29/04	Linda's office
Colin	Nov. 3/04	Linda's office

*Participant Observations***Thompson Family**

Participants	Date	Setting
Margaret John	Nov. 24/02	Family open house
David	Dec. 10,/02	Coffee shop
Margaret John	March 20/03	Visit in home
Margaret John	Sept. 11/03	Visit in home

Tanaka Family

Participants	Date	Setting
Rose Tom	April 09/03	Family home
Rose Tom Linda Maria Colin	April 11/03	Family home
Rose Tom	May 22, 2003	Lunch in restaurant, drive
Rose	Aug. 27, 2003	Lunch in restaurant, drive

*Conversational Recordings***Thompson Family**

Participants	Date	Setting
Margaret John Barbara	Jan. 15/03	Lunch in family home
Margaret John Stephen	March 25/03	Dinner in family home
Margaret John David Angela Christine	May/ 03	Dinner in family cottage
Margaret John Angela Christine	May/03	Dinner in family cottage
Margaret John Angela Christine Grandchildren	May/03	Dinner in family home (video)

Tanaka Family

Participants	Date	Setting
Rose Tom Barbara	June 26/03	Coffee in family home
Rose Linda Maria	Aug../ 03	Lunch in restaurant
Rose Maria	Aug../03	Afternoon visit in family home
Rose Tom	Sept./03	Dinner in family home
Rose Colin Grandchildren	Sept/03	Visit in Colin's home
Rose Colin Grandchildren Colin's wife	Sept./03	Colin's home (excluded)
Rose Tom Linda Maria	Nov./03	Dinner in family home (video)

APPENDIX D

KEY TO TRANSCRIPTION

Phrase boundary markers

- , Slightly rise as in listing intonation
- ? Final rise
- / Slight final fall suggesting temporary closure
- // Final fall
- Truncation (i.e., abrupt ending)
- _ Level ending (i.e., with no discernible rise or fall in intonation)

Timing features

- .. Pauses of ≤ 5 second
- ... Pauses of < 2 seconds
- <n> Duration of pauses ≥ 2 seconds
- = Indicates overlap, placed at beginning and end of overlapped segments
- == Latched utterances (i.e., immediately following but not quite overlapping preceding utterance).

Prosodic features of talk: Intonation within phrases

- [/] Rising intonation (not at a phrase boundary)
- [N] Falling intonation
- ~ Fluctuating intonation

Prosodic features of talk: Voice quality

- [f] Louder than surrounding talk, [ff] means much louder, [fff] very loud.
- [p] Quieter than surrounding talk. [pp] means much quieter, [ppp] means very quiet
- [h] Higher pitch than surrounding talk
- [l] Lower pitch than surrounding talk

Prosodic features of talk: Speech rate and stress

- [ac] Accelerating, faster than surrounding talk
- [dc] Decelerating, slower than surrounding talk
- :: Lengthened utterance
- * Stressed: normal prominence
- ** Stressed: extra prominence
- [[[Indicates exaggerated rhythmicity, placed before each beat

Strategies for marking how particular features are related to talk

- { [] } Nonlexical phenomena (vocal and nonvocal) that overlay talk
- [] Nonlexical phenomena (vocal and nonvocal) that interrupt talk
- # # Demarcates extratextual information (e.g., #business name# indicates that a real name was spoken)

Non-talk vocal features that accompany talk

- [hh] audible exhalation (check these as they are routinely used elsewhere)
- [.hh] audible inhalation
- [heh-heh] indicates phenomenon, not the quality, of laughter – often overlays speech

Analyst's strategies for denoting problematic stretches of talk

- () Unintelligible speech
- di(d) A good guess at an unclear segment
- (did) A good guess at an unclear word
- (xxx) Unclear word for which a good guess can be made as to how many syllables were uttered, with each x representing one syllable
- [p/nw] phonemic paraphasic error resulting in a non-word. This is marked to indicate that it is not a typographical error and, also, that as a clinician I attach a particular significance to it.

APPENDIX E

TANAKA FAMILY TRANSCRIPTS

Transcript 1: Christmas

1. R: he's *got tea/
2. L: *I know/ *I need some//
3. R: *oh oh/ you got a *cup there?
4. L: =*yeah, =
5. R: =oh/ = *I see// [sound of pouring]
6. L: um::_ <3> *okay/ *Christmas// right?
7. T: =*eh? =
8. M: =mm*hm,=
9. L: ..*Colin-..*you know that Colin and *Anne are gonna go
10. to *Peter and *Sue's for Christmas this *year?
11. R: *Peter and *Sue's?
12. T: oh//
13. L: yeah// you =*know who = they *are?
14. R: =(where's) *that/= yeah//
15. L: Pe-*Peter is Anne's *brother//
16. R: yeah,
17. L: so *they're gonna go *there for Christmas dinner/=this =*year//
18. R: =oh//=
19. but where *is that// where do *they - =still live in North =Van*couver?
20. L: =where do they *live? =
21. M: ={[p] (x)/ yeah//}=
22. L: =yeah/ = yeah/ *just five *minutes from here//
23. R: =oh =*I see//
24. L: =yeah//=
25. M: so *we're gonna -
26. L: well - {[sounds of serving out food] <5>*we thought/}
27. ...we'd come *here for Christmas dinner,
28. R: mm*hm?
29. L: {[l. p, ac] like we *usually do,}
30. R: yeah/
31. L: =inste-=
32. T: {[to M, reaching for something]=may = *I have a_ }
33. L: in*stead of having...*turkey/ <2> we'll have *ham//
34. ..'cause it's *easier?
35. R: yeah/.. **ham is nice// you get - you *know? you get a.. a-
36. M: mm*hm/
37. R: ..it's...uh..with the *skin *on,
38. L: yeah//
39. R: ..un*less the butcher *takes it/

40. I *don't think – you- *you know how you-
 41. M: =you sc=
 42. R: =you = put the *cross on?
 43. M: yeah/ you *score it?
 44. L: yeah//
 45. R: *score it? and then you *make a little..uh.. *thing/ with the um.. *sugar:._
 46. and =um_ =
 47. T: =o*kay =you guys/ *help your=*selves//=
 48. R: =..what = =*ever= it is//
 49. M: =sure//=
 50. like a *mixture// =yeah// =
 51. R: =*mixture,=
 52. T: help your*self/ you guys,
 53. L: yeah/ {[f] so I *thought what I'll *do/
 54. is.. =*cook it, at- =
 55. T: {[moved away from the table] = I *guess I'll=put some *more in//}
 56. L: {[~] *home:.,}
 57. R mm*hm,
 58. M: yeah?
 59. L: and then I'll bring it *here//
 60. R: {[pp] oh *oh *I see}
 61. T: {[back at the table][sighing]=oh *yeah:./=}
 62. M: =yeah/ =
 63. T: =so are *you gonna have - =
 64. M: =and *I'll do:: = the po*tatoes mashed, and maybe some –
 65. like a *squash/ or something like *that//
 66. L: {[sound of tea being poured][p] thank you/}
 67. R: *I've got two squash now/
 68. M: {[p] you want some more *mushrooms mom?
 69. there's *lots of *mushrooms here/

[C/RMLT/8.13: 9:42 – 11:07]

Transcript 2: Thailand

1. T: *I might *ask you to.. check *into/ uh... *using *airmiles?
2. M: *okay/
3. T: from Van*couver..to Ha- ..Hono*lulu,
4. M: yeah/
5. T: *but/..from Hono*lulu,..on to *Thailand/
6. ... {[ac] because there's *no point in going to..Hono*lulu/
7. and then going back this way, and then going to *Thailand//
8. ..because *Bill and I have been talking about}... *Thailand//
9. M: well =*why= don't you continue to go to *Thailand=with *Bill/ =
10. T: =so/ = =so that's (*it)/ =
11. and then *Mom and I can come back, into Van*couver//
12. or do you *want {[heh-heh]me to go to Thailand *too//} [heh-heh]
13. T: well it's *kinda up =the uh-=
14. M: =is =*that what you =*want? =
15. L: =[h] but =
16. ..*don't you think it would be *better to *go to Thailand/ *first::?
17. ..and then-
18. T: drop=*back,-=
19. L: =and =then come back/
20. and spend a=re*laxing={[dc] kind of week}, =
21. T: =yeah/ *that sound-*that's an i*dea//=
22. L: in =Ha*waii?=-
23. M: =although =*Thailand is a *lo::ng *flight/
24. T: =it *is/ *yeah//=
25. M: =and I think =it's *too long for *mom/
26. y- *you don't like *planes that much/ *do you//
27. R: {[h] no it *doesn't *bother me,}
28. T: =[heh-heh]}=
29. M: =no? =
30. L: well I mean *wha-/. the- it's *gonna be *long either *way/ right?
31. I mean if you {[heh-heh-heh]*go there/ it's gonna be-}
32. M: yeah/ but it *breaks it *up// ..yeah that's *true/
33. L: =why *not/ =
34. M: =I'm *gonna= have to come *back/ *yeah// ..the flight *back/
35. L: yeah/ the flight - you've got the flight *back/ =right?=-
36. T: =[hhh]=*I don't know/
37. L: but *that's what *I would do,
38. M: =but-=
39. L: =and= then *have more of a re=*laxing,=
40. M: =yeah/ =
41. L: *you know/ where *everybody {[heh-heh] speaks *English,}
42. M: ==*how long are you *thinking of/ this whole *trip//

43. T: ..*couple of *weeks//
 44. M: mm*hm/
 45. T: but *this is very-..*not two weeks in Ha*waii/
 46. { [p] I think-}..*oh/..*four days or so/ =*five days/=
 47. M: =*okay/ =
 48. T: ={ [pp] in Ha*waii will be long enough/ *yeah/ }=
 49. M: =and then..a bit *longer//..*okay// =
 50. { [h]*okay/ }
 51. T: =='cause I *know..every *inch of-
 52. L: ==have *you *been to =Thailand?=
 53. T: =Hawaii/ =
 54. M: ==yeah//
 55. =*I =just think it's going to be/ a little more *difficult in *Thailand,
 56. T: =yeah/=
 57. M: and it's a *little bit *more um/..it's =*hot,= and it's.. *bustling,
 58. T: =yeah/=
 59. M: and it's not-..you *don't know the *language,
 60. and it's a *little bit more *stressful? and I don't- ..I -
 61. that- ..*that's the only thing that my con*cern is//
 62. L: would *Bill go with *Anne?
 63. T: { [~] yeah::, }
 64. L: { [h] well then *that would be- }
 65. M: yeah/
 66. T: *anyway/ *this is all up in the *air,
 67. M: =*okay/ =
 68. T: =*something= that has to be *straightened out/
 69. but/..the first..*thing is/ I've *got to find out about the *air/
 70. *whether ..uh..*whether I can arrange-
 71. *maybe I can look *after that/
 72. L: *you liked Thailand/ *didn't you Rose?
 73. T: yeah/ *I'll see if I can-
 74. R: { [h] *yeah,..*I liked it/ }
 75. T: uh..do *you know how to turn that uh... *unit off?
 76. { [pp] because *I think it's just about done/ *isn't it?
 77. M: yeah/ yeah/ it's *probably -..*it'll run *off so/...{ [ppp] it's *fine/ }
 78. L: well we *might as well *turn it off/
 79. M: { [pp] yeah I *guess/ }
 80. L: { [pp] so it's *not- }
 81. T: *so:: *anyway,...that's-
 82. L: { [ac] *I gotta get *going/ }
 83. M: { [pp] *okay/ }
 84. L: { [pp] *okay/ }
 85. T: that's-..that's..*that's in the *works, ..um::_
 86. M: *which - which one did you want to - did *you want to -
 87. if *you had a *choice between Ha*waii and *Thailand/
 88. *which one would you wanna *go to//

89. <3>
 90. R: {[h] um::...I *like *Thailand,..}
 91. M: mm*hm, ..=do you wanna go *back?=
 92. R: =um::... because =
 93. there was *kind of a lot of *villages, and- and things,
 94. and *people were more... uh.. *easy to *talk to,
 95. M: mm*hm,
 96. T: {[~]**talk to?}
 97. M: {[p] yeah/}
 98. L: well *they spoke *English,
 99. T: =*hmm?=
 100. M: =yeah/=
 101. did you- would you prefer *Thailand?..or..or..Ha*waii//
 102. L: well *they can do *both, *she can do *both,
 [C8/RTLM/ 1:03:03 – 1:05:53]

Transcript 3: Swans and Ducks

1. B: so - so the *parks board had to *build a [heh-heh]
2. had to *build a *fence around the *=swans' *nest? =
3. R: ={[~] *oh::: =
4. T: =heh-heh =
5. B: so that *people would be pro*tected from the *=swans/ =
6. T: = {[heh] the *swans/} =
7. B: *not =the other =way =*round/ =
8. T: =not- *yeah/=
9. R: =way *round/= *yeah/
10. B: I *don't think they were worried about *people -
11. ..I *think they were just worried about the *swans at*tacking=people/ =
12. R: =at*tacking/=
13. =yes/ =
14. B: =because= if they walk *=into *range/ you *know? =
15. R: = oh:: *yeah/ oh **sure::// =
16. B: *=I wa=-
17. R: =(to be)= because - with their *big *=heads,=
18. B: =*oh/ =
19. R: and their big *things,
18. B: =they're =
19. R: =they'd = be *going like *this/ you know?
20. B: they're so *ugly when they're *doing that/ ..don't you *think?
21. R: yeah/
22. B: when they've got their *heads out,
23. =and they're- =they're.. at*tacking, =and- =
24. R: =mm*hm, =
25. B: *yeah/
26. <2>
27. I was *thinking/..you *wonder how they managed to get the *nest-
28. the **fence around/
29. without the *civic workers getting.. attacked by swans as *well/
30. R: {[p] *oh/..oh *I see, {[pp] yeah/}
31. B: so_
32. R: ... {[h] *we had about} ..four or six little baby *ducks/
33. and one *mother one/
34. T: yeah/
35. R: *swimming in our *pool//
36. T: =[heh-heh-heh]=
37. B: =*oh:/ =
38. R: in the *morning I look *out/
39. {[ac] I *always *do that first thing in the *morning/
40. to *make sure that there's nothing in there/ =*dead/

41. = or a *bird or something/}
42. B: =yeah, = == yeah?
43. R: and *here's the mother *duck, ..and *then uh..uh
44. ...she-.. she would *go around like *this on the *edge/
45. B: mm*hm,
46. R: so that-..the- the *little ducks-
47. {[h] the *little ducks} were *just like *this/ =you *know? =
48. B: = {[h] *oh::/} =
49. R: so that *they were trying to *keep up with the *mother duck/
50. T: ==*these ducks were-... *obviously unable to *fly yet/
52. B: uh*huh?
- [two minutes thirty-five seconds of conversation here, with Tom as main speaker]
53. T: *they were there for maybe an *hour?
54. B: *okay/
55. T: yeah//
56. B: ..and you *never saw them a*gain/
57. R: no/ so they just *happened to walk through.. the *road or something,
58. or um..some *dogs, you *know?
59. B: right/=right// =
60. R: =and uh-=
61. B: *I thought maybe they'd actually been *living in your yard,
62. the whole *time/ and then when it was *time to have the =*ducks - =
63. R: =(ducklings)=
64. B: *okay/
65. so *now I have a place to teach my =*babies=to =*swim,=*you know but-
66. R: =(xx) = =yeah/ =
67. T: it =*must= have been-
68. R: =we = had rac*coons/
69. T: it *must have been a *nest somewhere/ =*very close =*somewhere/
70. R: =it *could be/=
71. B: yeah/
72. T: because we never *did see/ the *mother duck/
73. R: *no/...but I *looked under that *tree we had/
74. *what was that *tree we had//
75. T: ...oh/ *you're talking about the rac*coons/ *yeah//
76. R: yeah/ *I happened to *look/ under*neath/..that uh..*tree and the *branch/
77. and then *I *see about *half a dozen **eyes::/ **staring at me/
78. B: *hmm/
79. R: *that was because/..it was =*dark/=
80. T: =ki- = *kiwi plant//
81. R: yeah/ *kiwi plant//..*anyh-..**oh::/ they were *looking at me/
- [C/RTB.5.26.40:42-45:26]

Transcript 4: Photo Show

1. L: {[h] did you *go to that}..um/...*photo,...um...thing? with um/...*Bob?
2. ==that *photo..*gallery?
3. T: hmm? =oh *yeah/{[p]..yeah yeah//}=
4. L: =or..that *show? =
5. T: yeah/ yeah/
6. L: what was it *like/
7. T: it was *good/
8. ex*cept that this uh..=*lady/ =
9. M: =it was = the in*ternment uh.. *photos/= ma,=
10. T: =*she=
11. just *talked and *talked// *you know? when *one gives a *talk/
12. *maybe *twenty minutes *you know/ at*tention span/
13. T: =just- =
14. M: =yeah/ =
15. L: =mm*hm/= I *know/
16. T: but *these people who are -
17. M: {[p] *they don't know/}
18. T: *no no/ but they- *they should -
19. they- they- they - *they get up in *front of people, uh *talk,
20. and *this lady was-
21. I *think she's probably {[dc] as*sistant prof or something} at UB*C/
22. M: =mm*hm,=
23. T: =..or - I'm= sorry/ Simon *Fraser now//...*she should know *better,
24. *she -.. went for about-.. over an *hour//
25. L: {[dc] *holy =**smokes//=}
26. T: =yeah// =
27. L: *I didn't *know it was a - um::_
28. M: ==she probably thought it was like a *class/ =you =*know?
29. T: =hmm? =
30. they're =*used= to doing classes/ =for =about =*fifty= *minutes//
31. T: =mm/ = =yeah/= =well-=
32. =people- they- =
33. R: =*I felt ...sorry= for the /haku*jjin/ people that came and *sat there/
34. because-
35. T: ==*well/ so-
36. L: ==*why//
37. R: but- *you know / we *knew what she was *talking= about, =
38. M: =yeah/ =
39. R: =like Lemon *Creek and all *this-=
40. T: =no *no/ the *fact is/ = *people's= at*tention span/
41. M: =hmm/ =
42. T: *you know/

43. L: ==is *basically= as long as your= your- your- butt can.. =*take//=
 44. T: =goes a*way// = =yeah// =
 45. L: {[ac] did *you en*joy it Rose?}
 46. R: {[h] um..oh/ in {[~]*ways},
 47. because they *had a lot of *pictures on the *wall::, *you know/
 48. L: =yeah/ =
 49. R: =around= the four *walls,
 50. T: but the uh- the uh... *thing was/
 51. {[p,ac] and I *know it was-} *one person al*luded to/
 52. was that the *pictures by [clears throat]... *what's the name?
 53. Ans- uh
 54. L: *Ansel *Adams?
 55. M: oh *yeah//
 56. T: ...An-... *what's that *famous guy// *Ansel-
 57. L: ==*Ansel *Adams//
 58. T: *Ansel *Adams/ yeah// <2> that..de*pict a *picture/
 59. *you know/.. of the *inmates? *oh::/ *everybody's *smiling,
 60. *beautiful black and white *pictures/
 61. *everybody's {[heh-heh] happy}, like you *know?
 62. and so *somebody/.. from the *audience/ *did uh..bring this *up/
 63. L: mm*hm,
 64. T: that it *wasn't a *real..true re*flection/ of what it was in the *camps//
 65. L: *hmm//
 66. T: *you know/
 67. M: yeah//
 68. L: well *his must = have been *pictures =of A*mer-
 69. T: =[clears throat]but *he- =
 70. L: A*merican camps?
 71. T: huh?
 72. L: {[dc] were *his... *photos..of..A*merican in*ternment camps?}
 73. T: one..*one of them//
 74. M: =mm/ =
 75. T: =*one of= them/ called *Mazanar/
 76. L: oh *that's that one that's *just down-
 77. T: ==yeah/ well we-
 78. L: ==*(ten)//
 79. T: ==*visited the..that *area//
 80. L: *you know that *snow falling on *cedars?
 81. M: mm*hm/
 82. L: *that's where the.. in*ternment took *place//
 83. M: {[pp]mm/}
 84. L: {[pp] I *think,}
 85. <2>
 86. T: there were *ten thousand people there//
 87. L: ==what did you *think of the show/ *Rose?
 88. R: ...the *one that we saw =*here?=

89. L: = mm/ =
90. R: {[h] oh/} I *guess it was o*kay,
91. ...*you know/ there was nothing.. *new or anything,
92. except that.. you *did see pictures..of certain *areas/ and things like that//
93. L: hmm/
94. ...did it re*mind you of anything that uh.. *you experienced here?
95. R: *no/ because *this was all-... *you know/
96. we'd been to {[dc] *[Tashmi, and *[Sandon,
97. and [and ([knew where) New *[Denver was,*[Rosebery,) and all that/ but,
98. L: mm*hm,
99. R: the *one that they showed that *night/ ..about.. two three *weeks ago/
100. uh..there *wasn't anything *new//
101. L: was it *all just that one *camp then? all *photos from that just one *camp?
102. T: yeah//
103. L: ==*oh::/ I *thought it was more of a -
104. T: ==well *this-
105. L: ==um::_
106. <2>
107. T: =this *lady that uh =- who *spoke/
108. L: =*wider- mm*hm? =
109. {[dishes clattering] <3>
110. M: {[p] would you *like-}
111. R: =yeah/ *just put - that's *fine/ yeah// =
112. T: =*showed about *six or eight *slides/ =
113. L: mm*hm?
114. R: that's *fine//
115. T: *of-
115. M: {[p] *tofu?}
116. T: um_
117. R: okay, yeah/ anything- just *give me a little *bit/
118. =uh..*juice on that, *that should be enough/=
119. T: =of *photos taken..in some of the *camps/ =
120. =you *know? up here in = *Canada/ but-
121. M: =*I'll get you *tofu// =
122. R: thank *you,
123. M: *juice?
124. R: yeah/ =*just some *juice {[pp] (xxx) =
125. T: =*they were just *regular - I mean=
126. *you could= take a look at my *album/ and see some of those *pictures//
127. L: *how many *people were there//
128. T: mm..*full *house,
129. L: well *that's good/
130. T: *I'd say about... *fifty?
131. L: {[p] *that's good//} {[ac] is *that show still *on?}
132. T: *oh yeah/ I *think so/ but I *don't think the-
133. L: *lecture//

134. T: the *lecture is =still there/=
135. L: =you know=*what? I don't *wanna go to the *lecture/
136. M: =yeah/ =
137. L: *I just= wanna take my *time/ =
138. M: =yeah/ *I wanna see the-= ==*we should go/
139. {[p] *we should go//}
140. R: yeah/ *now that they have all the *pictures *too/
141. M: yeah?
142. R: yeah/ black and *white,= on the *walls/ you *know?=
 143. M: =yeah/ *I'd like to see *that/ =
144. R: and from *different *places, New *Denver, or *Tashmi, or-
145. M: {[h] so *you were-} you were in *Rosebery/ *right mom?
146. R: yeah/ *Rosebery//
147. M: *Rosebery/ and -
148. R: ==mm*hm,
149. M: ==did you *stay there the whole *time?
150. R: ...=uh::=
151. M: =with your *family?
152. 'cause I *went - I *rode through *Rosebery//
153. R: yeah//
154. M: and *Sandon/
155. R: =mm*hm, =
156. M: = {[p] to that- =uh - the- =
155. L: =did *you go= to see that in *ternment thing?
157. M: ==yeah/ =the *nikkei//=
159. L: =that *centre?= the *nikkei thing?
160. M: I've *been through there be*fore//
161. L: mm/
162. M: ==*that was in New *Denver// but *Rosebery -
163. {[h] we *ended up doing the trail/ and we *kinda just rode *by/}
164. R: =mm*hm,=
165. M: =it said a =*sign/ to *Rosebery? but we *heard there wasn't much *there/
166. that there was *just a *store//
167. R: oh *yeah// yeah/ i- there was ju- *one= general= *store there,
169. M: =yeah/ =
170. R: and then be*side it was a *railway *track,
171. ..and *then= there was= a *bridge, =
171. L: =was *that- =
172. ..that Kettle *Valley railway?
173. R: huh?
174. L: was *that that Kettle *Valley railway?
175. M: {[p] yeah/}
176. L: really?
177. M: = {[p] yeah/} =
178. R: =*no/ =it *wasn't the =Kettle= *Valley uh...uh *bridge/
179. M: =*oh/ =

180. R: but there was *still a *bridge/
 181. M: yeah/
 182. R: and um..there was a *railway/
 183. M: yeah/
 184. R: so..the *trains/ about *twice a *day/..we could *hear them//
 185. and then..when they *went *past..the..the *bridge/,
 186. and you *go a little bit/..and *then there's the *first ave-
 187. we *used to call it the *first...not *avenue,
 188. the *first...what*ever it is/ and then the *next one/ was the *second one//
 189. ..because they built the *first..*you know/..area *first,
 190. and then the *second one//
 191. M: mm*hm,
 192. R: uh..and *these all came from - ..I *guess they came from Van*couver,
 193. and *some of them maybe *didn't want to *stay in Slo*can,
 194. =={[ac]what*ever it is *anyway}// but..they have *built these *you know/
 195. *wooden..*houses//
 196. M: =mm*hm,=
 197. R: =they = were *all:...a*like// um_
 198. M: and *you st- ..your- your - your *family was there//
 199. R: yeah/ *we were-
 200. M: and how *long- =how long- =
 201. R: =we were in *Rosebery,=
 202. M: =for *how long- =
 203. R: =but we were =*lucky, =
 204. L: =[h] but*I= thought}-
 205. *I thought that you were in um:._
 206. M: *Tom was in Lemon *Creek//
 207. L: I *know/ but *I thought Rose was in New *Denver//
 208. R: well we went to *school to New Denver/ we *had to walk *four *miles//
 209. *every *day,.. *going, =four miles, =
 210. M: =that's *right/=
 211. R: and *four miles coming *back//

[C:RMLT: 23:10-28:55]

Transcript 5: The Kootenays

1. M: So Ma? <1> um...I *just came back from that bike trip?
2. <3> and I picked up some *postcards/
3. ..of the *areas I went to/ and I thought you might remember
4. ..*some of these *places where you grew up?
5. ..where you grew *up?<2> ring a *bell?
6. <3>
7. R: *oh yeah/ New *Denver,
8. ..'cause *we had to *walk about four *miles every *day from uh..
9. *Rosebery to New *Denver//
10. M: *yeah/
11. R: so =*during= our *lunch hour,
12. M: =I took- = yeah,
13. R: we'd go -I *wouldn't say down *town/ it was just a - like *these kinda/
14. um::_
15. <5>
16. L: =Rose-=
17. R: =I =*liked it there/ *people were very *nice//
18. L: {[h]did your *mum...have t*b?}
19. M: <1> *no/ I don't *think so/
20. L: {[h] be*cause..I *thought} .. you *said that/
21. ..you re*membered driving *into - {[ac]..or *taking a bus *into}
22. ..uh..**Nelson//
23. ..they had a t*b sana- ..sana*torium? ..sana*tarium?<1> sana*torium?
24. R: *no but.. {[h] she *didn't have t*b then}/
25. L: =[ac] then *why would she-=
26. R: =it was - = it was dia*betes//
27. L: dia-**oh::/ =it was-=
28. R: =she had= dia*betes//
29. L: so *that's why she had to go in//
30. R: yeah/ she- she had that/==*that I know for *sure//
31. M: {[p] mm::/.. *sugar diabetes/}
32. R: ..but *luckily, ...it uh..(it -*even though she would have) diabetes*two/
33. there's.. *one two three different *kind of um-
34. M: ==yeah/
35. R: you know some people.. *have it/ and =*still::=
36. M: =yeah/ =
37. R: ==not have to go to *bed/
38. ..or =what*=ever/
39. M: =yuh_ =
40. L: did she:: um/... *she didn't have to take-..take *needles though/ *did she?
41. R: huh?

42. L: ...she *didn't have to take *needles?...or- or *shoot herself?
 43. R: ==*oh yeah/
 44. =she *al- =
 45. L: =she *did? =
 46. R: no/ *always.. =*shot herself//=
 47. M: =so she was =*insulin =de*pend=ent//
 48. L: =*oh::/ =
 49. R: yeah/
 50. M: so *we all gotta *watch/
 51. L: I *know:://
 52. M: {[p] our sugar//}
 53. R: she'd (*grab a hold of her *skin)/ ..and then..then push it *in (like)/
 54. M: *Tim's dad has..*he's taking insulin//
 55. L: really?
 56. M: *he's had diabetes for the last *ten *years/
 57. {[l] but.. he *hasn't been very good at.. con*trolling it//}
 58. <2>
 59. M: do you remember *that? Na*kusp?
 60. ..so *pretty- we..we..we *did a *short um..trip from Halcyon *Bay?
 61. it was around *thirty five kil*ometers into Na*kusp?
 62. {[l,ac] *usually we did around *eighty ks a day//}
 63. but ..*this time we *stopped there/
 64. we- we *liked it- it was =*right= near the *water?
 65. L: =yeah?=
 66. M: it was *kind of a tacky *area/ but the ar- the *water was =fine// =
 67. L: =*thank= you/
 68. M: ==oh *thanks/
 69. {[h, p] can *I get some chili oil?}
 70. W: yeah/
 71. M: *anyways we um..*went to the *waterfront and played *volleyball,
 72. ..=with =some *locals?
 73. L: =oh::/ =
 74. R: oh yeah,
 75. M: on the- on the um *beach? {[ac]'cause there was a *volleyball net up there/
 76. and I just *asked, and then we went..and there's *lo::gs that are around?
 77. R: oh yeah,
 78. M: and you - you *climb *on them/ and they're *all -
 79. .. they're *kind of strung to*gether with some - with um *chain/
 80. R: =with a *chain/ yeah/=
 81. M: =metal *chain/ = but you can *jump from one to the *other/
 82. and go **all the way on the= *outside/ =
 83. R: =yeah/ =
 84. M: but the- the *logs **roll/
 85. R: oh yeah//
 86. M: /.. so you have to be *balanced/
 87. =so it = was **good//

88. L: =oh::/ = mm/
 89. <4>
 90. L: {[pp, background noise] thanks//}
 91. <2>
 92. M: *where are you looking-..*what are you looking at *now/ mum?
 93. R: hmm?..well I'm *just trying to.. *see if I could uh.. re*call some of these –
 94. {[h] *some of *buildings (xx) just seem to-
 95. M: is it *Sandon?
 96. R: *this is Sandon {[~]*here,..
 97. M: {[p] okay/}
 98. R: but *I never ..*lived there/
 99. ..we *went to uh..visit my *uncle and uh
 100. ..*auntie when they *lived..in*Sandon/
 101. {[ac, l] because they *had quite a bit of Japan*ese there *too/}
 102. M: ==yeah/
 103. R: and um..uh..*this uh/..*not this *summer/
 104. {[h] I *think it was about *last year?} when *Tom and I –
 105. when we went on a *trip//
 106. M: oh/ it was *two years ago//
 107. R: yeah/.. we *went to *Sandon// ..and um..we *took our *time,
 108. ..it was *kinda nice/ *nice weather and *everything/
 109. <5>
 110. M: I *thought I could take *pictures/..but *those are ..*better/
 111. = *postcards=are better//
 112. R: =mm*hm, = {[p] *that's right/ *yeah/}
 113. and *not only that/ it's got *on here/ ..Na*kusp, *you know/
 114. M: yeah/
 115. R: all *that kind of thing/
 116. <3>
 117. R: now/ I'll *put these..so they don't get *tea on it/ {[p] or.. whatever it is//}
 118. M: {[h] New *Denver was nice,
 119. ..did *you spend much time in New *Denver?}
 120. R: {[h] um::}..well in New *Denver/
 121. ...we *walked the four miles from *Rosebery every *day//
 122. ..to New *Denver,
 123. M: *why//
 124. R: huh?..because we didn't *have a s- a *high school//
 125. M: *oh so it was a *school//
 126. R: yeah/ *school//..so uh.. but the *school..was right *in New *Denver,
 127. ..{[l] well you don't *call it a *city/
 128. ..it was just a *small..*place//}
 129. but actually uh..the *Roman Catholic *people/
 130. ..um..let us..have the *use.. of this..place,
 131. it- it *wasn't a *church,
 132. ..but uh..there were *people uh..uh...*what do you call/..*sisters (kind of)/
 133. ..*they lived there, <2> and *next to it – the *next one,

134. was where the..the *fathers..you know/ the *men/
 135. *they don't stay in the same *place/ ..{[p] *so it was good//}
 136. <2>
 137. M: I *like New Denver// it was a- *you've been there/
 138. L: *I went there..two *years ago//
 139. um..I was at a ..conference/ =in - in =*Nelson? and on the way *back,
 140. R: =oh/ mm*hm,=
 141. L: we um..stopped off at..the um/..this thing/..*you know that um/...*nikkei?
 142. M: yeah/
 143. L: place?
 144. R: oh/ the *nikkei/
 145. L: yeah/ ..but..I *didn't see your *name there Rose/
 146. but..*you weren't in New *Denver/ right?
 147. *you were in um::/
 149. M: *Rosebery//
 151. R: *Rosebery//
 152. L: *Rosebery//
 153. M: ==it's *only four miles a*way/
 154. L: yeah I *know but- ..the- the- the *people that were in*terned?
 155. R: =yeah?=
 156. L: =they = *all had their *names up/ right?
 157. R: =oh is *that right//=
 158. L: =on that *wall? but they *didn't have *Rosebery I guess//
 159. ..'cause *Rose's.. family wasn't there//
 160. M: ah//
 161. L: ==..I *looked//
 162. M: well *Lemon *Creek is really pretty *too// =that area?=
 163. L: = yeah/ =
 164. that's a *ghost town now//
 165. M: ==yeah but.. well just the wa- *area/
 166. R: ==yeah/
 167. M: ==the *water?= is -=
 168. R: =but= it's *flat//
 169. there isn't {[dc] *one *little **stump/}..on that *huge **acreage//
 170. L: ..mm*hm,
 171. <1>
 172. R: ..and they took *all the um.. *wooden down/...*homes/
 173. .. that were *all lined *up?
 174. <1>
 175. M: {[pp] *that's (so *good)/}
 176. <2>
 177. L: {[h] you *know um::... I was *talking to *Hannah?}
 178. M: {[p] yeah?}
 179. <2>
 180. L: you *know um/ <1> =Ellison=?
 181. R: =Janet's/= yeah,

182. L: =mm*hm/=
183. R: =yeah/ =
184. L: {[p] mm*hm/} and we were *talking about:t,<1> sh- did sh-
185. *first of all/ did you *know that she had a...like a... *heart attack kind of?
186. M: =yeah/ you *said that/=
187. L: =a *mild one? = a few *years ago?
188. R: who- *who had that//
189. L: *Hannah//
190. R: {[h] who?}
191. L: *Hannah//
192. R: ..=oh my =*gosh/she's so **young//
193. L: ..=mm*hm/= I *know/...so *anyways/
[end of quote]

[C/RLM.1.3: 2:10- 8:27]

Transcript 6: The Past

- <10>
- R: *he said he *really *liked uh- ..but he *wasn't a *fisherman//
1. <3>
2. the *only thing *is that one *time near Prince *Rupert/
3. the *storm was coming *in/..so he was- says **oh:: my **go::d/
4. I'm gonna *drift..towards a- A*laska//
5. and there were a lot of *fishing boat/..from U S *fishermen/
6. *somehow,..because the *storm was so *bad/
7. they kinda *came towards the..*British Col*umbian water//
8. M: mm*hm/
9. R: and he said *god they were awful..*drivers/
10. they *didn't seem to *care//
11. ...um <2> and *then,
12. <2> {[h] the *second time} he said was so *queer,
13. was that... *his boat was taken a*way/
14. *all Japanese *fisherman got their *boat taken away//
15. M: hmm/
16. R: and they *weren't given a *penny//
17. M: {[ppp] yeah/}
18. R: and *then he says...he was a *little bit out*side the *water//
19. ==*this is the {[sound of drawing on table]...} the *mainland,
20. [clears throat] be*cause the- [clears throat] the *way there was so *many/
21. ..he de*cided [clears throat]/
22. ..*I'd better start going in towards the... the uh *land/.
23. .near Prince *Rupert/
24. M: mm*hm,
25. R: and..*he have to go around Queen *Charlotte,..and *this was a pen*insula,
26. and it *wasn't too ..*far to the *land/..but he had to be *careful//
27. M: right/
28. R: and *then he says he...thought **oh my **god::/
29. he says I *wonder if I'm gonna *make it//
30. ,,and *then he says he looked *up/
31. <2> {[dc] 'cause there was *so much *water, and *wave,}
32. ...and he says- {[h] he says {[~] *that's my *new **island/
33. *that's my **boat//}
34. M: {[ppp] hmm/}
35. R: the *fish packer boat was *taken...=a*way/ =
36. M: =mm*hm/=
37. R: from the *=federal=*government,
38. M: =(xxx) =
39. R: but the *federal *government just *gve them a*way/

40. *all the Japanese *boat were given a*way//
 41. and *those people *pocketed/..=the =*money//
 42. M: =[pp] yeah//]=
 43. R: and *he said he *saw this *Vancouver-..the- .the:: _
 44. ...{[p] *something *island it was called/}
 45. M: ...{[p] *sea island? [ppp] no/}
 46. <3>
 47. R: {[h,pp] *isn't it *funny/..*Vancouver-}
 48. ..well *anyway/..but *he says/
 49. *all of a *sudden he says/...he saw this *boat coming to him/
 50. ...and he says/ {[h] my **god that's my **boat//}
 51. M: mm*hm/
 52. R: so *anyway he- ..I *guess you know/ when you're a *fisherman/
 53. ..you *have to know how to get a*way/
 54. M: yeah/
 55. R: so he:...*you know (sheered a*way)/
 56. 'cause *otherwise he woulda got *hit/
 57. M: wow/
 58. R: and then *that uh.. *fisherman/..*he was more *so *frightened/
 59. because *he- he *didn't quite know *how to operate the- *his own boat//
 60. M: yeah/
 61. R: and.. he said/ **oh my **god::/..if I go *straight/
 62. ..he- *he'll be the one that gets *wrecked/ because *his boat was
 *smaller//
 63. ..but *anyway/..*finally he (almost) *stopped his *boat//
 64. ..and *then..my *father **yelled at him with the **horn/
 65. and he says {[h] *don't get *frightened/ just *stay there/
 66. {[ac, p] and he says}I'll *give you-
 67. *I'm gonna *throw you the *rope/
 68. M: yeah?
 69. R: and then *tie:: it/..it has..*someplace where you can *tie your rope?
 70. M: right/
 71. R: and *that way, ..*now he's **safe//
 72. because my *father was gonna *help him take his *boat/.. *with him/
 73. to a *certain pen*insula, where there was a-
 74. where he knew ex*actly where it *was//
 75. because he *knew that *this fellow would {[dc]*ne::ver *make it//}
 76. ..by the *way he was *doing//
 77. M: {[ppp] mm*hm,}
 78. R: *anyway/ so he *told him again/ now {[dc] *don't *panic},
 79. and *make sure that your *rope is *properly {[p/nw] cleest}//
 80. because if *you just *throw it {[~] a*rou::nd}/
 81. you'll *get that *roped,..*wrapped around your *leg/
 82. M: right/
 83. R: and you - *you know/ you could be **thrown aboard//
 84. M: mm*hm,

85. R: and *then he says something/ I *guess he didn't *mean it/
 86. but he was *so **frightened/ he said {[h] *no he says/
 87. I *want to stay a*live/
 88. so..I *have to do *something//}
 89. ..so..uh..my *father kept *telling him/
 90. *no/ you *just don't *do something/...and he *kinda got *mad at him/
 91. he says/ now do you *want to stay a*live?
 92. he says/ {[ac] yes yes *yes}/
 93. ..so then *you do e*xactly what I tell you to *do//
 94. then *you will come to the *shore//
 95. ...and you'll *have your *boat/..in one *piece//

TRANSITION

96. ..and then...he *stopped for a*while/
 97. ..{[h] then he ap*parently *knew my father *too because.. *he used-}
 98. my *father was very *good/ ...*he used to um..um *go to um...
 99. *Queen *Charlotte,..and *buy things that these *fishermen/..
 100. *didn't *know quite *how to use their *boat?
 101. M: right/
 102. R: um..from going from the *mainland/ to Queen *Charlotte,
 103. and um..Queen *Charlotte would have.. um/...*lot of um/
 104. well they would have *food/
 105. but ..um *clothing, and um.. *rubber *boots, and um..the *top raincoat,
 106. ..and then they have to *fill their..uh *car with it all/ *gas= kinda= thing/
 107. M: =(gas?)/ =
 108. R: whatever *gas they need//
 109. so *he used to *go, and um...*buy the *oil,
 110. and then these *oil..uh..*people *knew my *father/ for *years and *years/
 111. and so *they give him/ uh..a kind of a *can?
 112. ..uh..={ [h] I *think *we have one/} =
 113. M: =(xxx) =
 114. R: yeah/
 115. M: gaso*line can?
 116. R: ==gaso*line that *holds uh hol- *you know,
 117. M: ==yeah_
 118. R: and *he had quite a bit in his *boat/
 119. because he *found it..was very..uh..*easy/
 120. *once he goes into..into a pen*insula/ and gets *three of those *cans/
 121. then he *doesn't have to *worry maybe/ ..for a *week//
 122. M: yeah/
 123. R: and then *also he says/ at the *same *ti:me he says/ these *fishermen,
 124. they don't *have anything//
 125. <2>
 126. because.. I *guess they can't be *bothered with it/
 127. or *don't want to ..*pay for the..con*tainer//

128. so *then they *also come to my..to my uh..uh *father and says/
 129. *{[\\]oh:::} *#name#san/ y'know *what? *I don't have any *gas/
 130. {[l] he say/} *I don't have *anything to put *into/
 131. ..and then he *knew right a*way they *want to-..and then he *also knew/
 132. that he would *never get it *back/ those people//
 133. M: hmm/
 134. R: so *he said it was the *hardest thing to *say//
 135. M: yeah//
 136. R: *but he says/ *you know/ don't *wo-
 137. don't for*get he says/ {[dc] I'm *working *hard,
 138. I have a *wife, and I have *five *kids,}
 139. M: ..yeah/
 140. R: ..*and I said/ I *need this *money//
 141. M: yeah/
 142. R: ..and then this... *fellow/... *clammed up right a*way,
 143. ..he *went ins*side his uh *thing,...and I *guess he felt *bad/
 144. he *musta been *crying/ *anyway he came out/
 145. M: [heh-heh]
 146. R: and *then he..a*pologized/..in Japan*ese,... *he said/ I'm so *sorry/
 147. he said/..I *just feel {[dc] *so *so **stupid}/
 148. and..and...to have be*haved like this/
 149. you *know?
 150. M: {[pp] mm*hm,}
 151. R: so my *father *told him/..*he was just a young *fellow/
 152. but he was *trying to..learn the *best he could *do,..and uh/
 153. so ..my *father told this *young *fellow/
 154. *he says/ well,..I'm *glad you a*pologized/
 155. to this other *fisherman/..and that..you mighta *learned a *lesson/
 156. and the *guy/..*he was just *young/..*then he said/ he started to *cry::,
 157. and *went to my *father, ..and said/..*I said/ *he said to him/
 158. ..that {[/]*ah:::}{[p] he says/} I *guess I just lost my *temper,
 159. and I *wasn't *thinking/
 160. M: {[pp] mm*hm,}
 161. R: you *know?
 162. M: {[h,ppp] yeah,}
 163. R: *and he says/ *I'm so *sorry,
 164. ..so uh..uh..my *father went to the *other fisherman/
 165. and he..*told/ what had *happened,
 166. ..I said/ you *have to ex*cuse that other *fellow/
 167. he came *crying to me, he *knew that he did something *wrong/
 168. ..and uh/ I'm *hopeful that he will *come to you and a*pologize/
 169. ..and then at *that moment he was *so up*set/ that he couldn't *do it/
 170. but *later in the *evening/
 171. ap*parently he *knocked on the- on his *boat/
 172. where the..little *lock was/ like a *door/ and he went *over to him/
 173. and he a*pologized//

174. M: {[ppp] hmm/}
175. R: and *he says/..I'm even a*shamed/ to even go *home/
 176. and tell my *parents/
 177. ..what I *did//
178. M: {[pp] yeah/}
179. R: so the *guy said/..well,..you *have the..*you know/
 180. ..the-..the *guts to go *home,
 181. and *say that you did something *wrong/
 182. ..and *also that you had come to *me and a*pologize/
 183. which is *hard/ *you know/
 184. ..if you don't (*need that)/ he said *something like that//
 185. *so...uh..when my *father had *talked with him, and *tried to tell him/
 186. {[h] *okay/ now you a*pologized, you've *learned your *lesson,
 187. and *hopefully/ you grow up to *be/..what you should *be//
 188. ..and *this little boy started to *cry::, and he says..he says/
 189. *I don't think I could go *home, and tell my..*parents/ what I *did//
 190. ..so my *dad says/..{[ac] *okay/..*don't worry/}
 191. *you and *I will just *go home/..go *over to your *place/
 192. ..told them e*xactly what had *happened,..and I said your *son,
 193. he was *quite *brave,.. he a*pologized,
 194. ..he a*pologized to my *father *too//
 195. to *say that he..*just wasn't *thinking//
196. M: yeah/
197. R: and he says/ #name#san,..he says/ *I learned a *lesson/ so she says/
 198. I'll *never,..for*get you/ he says/ I *really **learned something today/
 199. =so- =
200. M: =[dc] he = *seemed like a...*really..{[hhh] *wise **man/}
 201. <2>
202. *I don't know if To-..I *think Tom is going to be home at *seven Mom,
 203. R: most *likely//

[C:RM 3.27/28. 40:44-50:10]

Transcript 7: The Casino

1. <30>
2. T: well the ca*sino wasn't very - [clears throat] *kind,
3. {[eating] <3> } but..*I changed what/ three t- table three times?
4. different three {[pp] tables? {[pp] yeah/}
5. R: yeah/ *something {[ppp] like that//}
6. <5>
7. T: those *days when..you have *twenty? and the *dealer gets twenty *one?
8. deals at twenty =one? =
9. R: =mm*hm,=
10. T: um...[clears throat] {[I] *time to *go//}
11. <12>
12. R: um...[clears throat] {[h] *those people..uh...that *own that thing/}
13. T: what/..the ca*sino?
14. R: ca*sino/ =yeah// =
15. T: = {[pp] yeah//=
16. <2>
17. what a*bout them//
18. R: well *maybe not the *building/ if they have to rent it *out/ but-
19. T: the *business/ {[pp] yeah,}
21. <2>
21. T: what a*bout them//
22. R: so {[sound of cutlery] <3>}
23. {[h] um::} <2> they could *have those..ca*sino kind of like *thing//
24. ...they *have to have a certain *license/ *don't they?
25. T: yeah::, they *have to get the okay from the *government to *operate//
26. [clears throat] *not only *government/..I guess the... [hhhh] *city *too//
27. <9>
28. T: they *say about *five percent.. of the *people have *trouble/
29. ..*problems/ with the gambler// ..*you know/ gambling?
30. R: *oh::/..I *see//
31. T: getting - *problem gamblers//
32. <18>
33. T: {[h] *I often *wonder} how some of those **young...*people/
34. R: {[ppp] (how they *do it?)/}
35. T: with uh - *you know/ *wads of *money/
36. *five hundred *dollars/ a *thousand *dollars/
37. <4>
38. *how they uh/ <3> can af*ford it/ you *know?
39. <12>
40. R: *I was uh- *I was ama- I was *just kinda-
41. [clears throat]*I wasn't looking over their *shoulders/
42. but I was *looking.. at a certain *tables/ that they were on,
43. ...and I was a*mazed how --uh..so many *young people//
44. T: oh *yeah/ {[ppp] yeah//} and *that was in the middle of -

45. ...well *not middle of the *day/ but uh:... *obviously/.
 46. .they're not *working//
 47. R: or they *could be *high school boys,
 48. uh...I *guess they make some *money *working,
 49. and they *use that money to ..to *gamble I think//
 50. T: {[pp] mm//}
 51. <9>
 52. *lots of young – well I wouldn't say *lots/
 53. but a *few *young... **women/
 54. mostly Chi*nese/ =you *know?=
 55. R: =yeah, .. = I *noticed =that// =
 56. T: =the = young *ladies/
 57. uh *gambling/ and they're *not...uh..gambling *small/
 58. they're- *they're playing with a lot of *money/..as *well// [clears throat]
 59. <8>
 60. R: and they *always seem to have..lots of *money on the side//
 61. T: {[pp] yeah//}
 62. R: and when they're *bidding *too they *seem to put a lot of *money on//
 63. <20>
 64. so we like *gambling,
 65. <2> [clears throat]
 66. <2>
 67. d'you like *horse racing?
 68. T: huh?
 69. R: {[h] (xxx)/} do you like *horse racing/ =not =need to *gamble//
 70. T: =yeah/=
 71. {[eating] <14>}
 72. you know that *person that *phoned/ when we were *cooking/}
- [C/RT.4.21 18:49-23:53]

APPENDIX F

THOMPSON FAMILY TRANSCRIPTS

Transcript 1: Aphasia and the Piano

Introduction is J and M getting lunch to the table, B setting up the equipment.

1. B: well/ what do you *think//
2. J: well, [M laughs] *we could sit *down/ but uh..the *=stuff= isn't *ready yet,
3. B: =o*kay,=
4. *where would you like me to *sit/ Margaret?
5. J: ==right *there//
6. B: *this one?
7. J: yeah/ ...the other *two are..where *we usually *sit,
8. B: ...now would you - #nothing audible re why B breaks off, but it is not interruption#
9. M: {[h,t] *I}...I- I- I *wish to um..*be um/..um/ <10> I *wish to be uh/.
10. *talking a-...a*bout my um/ ..*playing the..the pi*ano//
11. B: *oh/
12. M: uh..*and I..I..*have um/...um/..my..a- a- a*phasia ..has uh/..um <4> uh/
13. <4> my..my a*phasia *has uh/...um/
14. J: <3> {[p] *made it..=hard for you to *read/=}
15. M: =m:- m:- m:: = ([muh- *mordi-]) *made it/
16. ..*hard for..for *me to uh/...uh..*read/
17. J: = {[pp] *music/=
18. M: =uh/.. = *sight reading//
19. B: and *that's how y- ...*that's how you *play/ isn't it?
20. M: =yes/ =
21. B: =I mean y-= *you don't-..you don't *play so much from just_
22. M: yuh/
23. <3>
23. B: *right/
24. M: I..I..I *used to um..um..*play the uh/..uh/..*corg/ at-...a-..and...and..and the *organ/
25. at um/ ..at uh/..St. *Mark's *College//
26. *and I..I..uh/..um...*that- that- that's..*made me um/..um/
27. <5> my- my- my a- a- a*phasia is um/..*made..that..*hard for- for me to *play/
28. B: {[l] yeah}// *when did you play the *organ at St. *Mark's/
29. M: a-..a-for- for- for um/..*nineteen *years//
30. B: *oh/ =and *when did you-= =that *long/=
31. J: = {[p] *that **long/ = ..**boy/ =
32. gee *I didn't even know it was that *long/}
33. *certainly during the *eighties/...and..*part of the *nineties/ I s'pose//
34. M: yes/
35. B: so *when did you *stop playing?..or *=have you-=

36. M: =er..uh..um =um..I. I *have = uh/
 37. J: =oh *yeah/ yeah/=
38. M: ..de- de*cided to uh/..*stop *playing//
 39. J: oh *yeah/ but it's not re*cently/ this-
 40. M: ==yes/
 41. J: ==*you stopped playing *there/ uh_
 42. M: yeah/
 43. J: *I don't know/ *five *six .. more *years ago// it's been quite a *while/
 44. M: mm*hm/
 45. J: since you've done it/ since you've done *that/
 46. M: yes/
 47. B: do you play *here?... at home?...still?
 48. M: uh...I- I-..I *don't p- play the..the..the uh/.. *corg/ or..the uh/ ..*harpsichord/
 49. J: *but you just play the pi*ano// {[p] you- =she = plays the pi*ano}//
 51. M: =yes/=
52. J: ==we have *three *keyboard *instruments//

C/MJB: 6.3: 1:28-3:24

Transcript 2: Four pianos, two hands, and two storytellers

1. B: did *you see..um/ <2> I *think it was called two pi*anos/
2. .. was it *two pianos four *hands,
3. as a *play, at the *playhouse? ..=with- =
4. J: =*yes//=
5. =yeah=/ we *did see that//... =yeah/ =
6. M: =yes/ = and =and uh-= I- I- um/ <3> I-
7. <3> *played.. a..a..a *part.. i- in *that um/...um/
8. J: ==oh *yeah/ [M laughs]
9. B: ..in the production?
10. M: in- in- = in- =the- the pro*duction// I-= I wa-=
11. J: =heh-heh= =mm/ =
12. M: I was uh/...um..um...um..[sighs]
13. J: uh..we were *just **sitting =in the= front *row/
14. M: =*yes/= yeah/
15. J: ..and..and they..they *cleared this with us *first/
16. but *some-..*I don't ..re**member what it **was/
17. 'cause it was *quite a long *time ago/
18. but..*they came **down/..* during the *play/
19. and *interacted with Margaret/ momen*tarily/
20. ==I *can't remember what it *was// what it was a*bout/
21. ..*I'd even forgotten that it *happened/
22. but *you clearly remember that it *happened//
23. ==*I don't remember *what it was that *happened/
24. it..it was *just some little *small thing,
25. ..=they *wanted somebody in the *audience- =
26. M: =uh..it- it- it- it *was = *to..um/
26. <3> um..*play..uh/.um..the-..the pi*ano with the *music/
27. <2> with..the- the *music/
28. J: {[ac] *you didn't go up on the *stage/ did you?}
29. M: *no/
30. J: {[pp] no/}
31. B: {[pp] no/}
32. <3>
33. B: *so did they want to *talk to you about that? or *ask you some_
34. J: *no/ no/ it- it wa- it- I *can't re*member//
35. it was *some little **incident/ in the p- in the *play/
36. which re*quired...=one of the *characters to-=
37. M: = {[f] uh..uh..it- it- it wa- }=was-...um/
38. <2>
39. J: {[sighs, p] I **don't re**member it//} I've *lost that//
40. ==I *know there was *something/
41. but {[heh-heh] I *can't} remember what it *was/
42. M: i--..i- d- *it was um/..um..the..um..uh..the..the *person's/..um/

43. <2>
 44. J: {[p] their *mother/ or something like that/ you *had to}-
 45. M: ==*yes/
 46. =yes// =
 47. B: =[pp] oh::/}=
 48. J: =they- they- = *they were *coming to con*sult/
 49. and she was *s'posed to say/
 50. ..you're- you're *s'posed to do *something or other or *whatever/
 51. =[heh-heh] it was-}=
 52. B: =oh::/ *yeah/ =
 53. J: it was *just a- sort of a ..*humorous =little =
 54. B: =right/=
 55. J: =..kind =of a**side thing/
 56. M: =[heh-heh]=
 57. J: {[heh-heh] but they picked *Margaret/}
 58. B: =oh::/ =
 59. J: =because we-= we *always tend to sit in the front {[~]*row,

[C/MJB.6.7: 9.31 – 11.57]

Transcript 3: Fruit Leathers

1. <3>
2. J: ==*very nice *person//=
3. M: =(x are- are um) = I- I uh..*made these um..*fruit leathers//
4. B: {[\} *oh:: *okay/*how do you do *those//...do you have a..
5. M: {[f] um_ }
6. B: {[p,ac] do you *have to =take -=
7. M: =de - =de*hydrate it//
8. J: we *have a de*hydrator//
9. B: *oh//
10. M: ==yeah//
11. J: *bought the *same time we bought the- the..the *mill//
12. B: *you have a lot of *gadgets/ *don't you//
13. J: =[heh-heh]=
14. M: =[heh-heh]=
15. J: but I mean that's - *that thing has done - *you know/
16. it's produced for..*twenty-three *years now//
17. B: =*okay/=
18. J: =pro* =duces those things *every *summer/
19. when there's *lots of *fruit around the *neighbourhood/
20. J: =that people= don't *want, =and =things like *that/
21. B: =uh-huh, = =right,=
22. J: =this is what =*happens/
23. B: =so is *that - = ==a *mixture of fruit?
24. J: yeah/ =well- =
25. B: =in this= one?
26. J: here// *do have one of those/= I =*think you will *like it//
27. B: =so - =
28. you *just peel them off?
29. J: yeah/ just- just- just *take it/ *peel one *off, .. and um
30. B: *thank you// =*that's= a *great way to get your *fruit//
31. M: = that - =
32. *this is um.. uh *apple/ ..uh..*plum and *apple//
33. B: mm*hm,
34. J: they *all have some *apple in them/ ..it pro*vides a good *base//
35. but *mostly they have *other fruits/ to pro*vide a bit more *flavour//
36. B: that's *very *good/...that's *very good//
37. {[sound of people eating]<8>}
38. B: the *plum really -
39. M: ..mm*hm,
40. <3>
41. I *have um..*blackberry apple, ...from my *bushes//
42. B: mm*hm,...I *wonder if people could do that..with *kiwi..fruit//

[C/MJB.6.18: 32:48 - 34:24]