THE EFFECTS OF FAMILY COMMUNICATION PATTERNS DURING THE MIDDLE PHASE OF ALZHEIMER'S DISEASE

by

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Dissertation submitted to the Faculty of the

Virginia Polytechnic Institute and State University

in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

in

Family and Child Development

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May, 1995

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(ABSTRACT)

The relationships between family communication about the illness experience of middle phase Alzheimer's Disease and caregiver depression were examined in this study of 29 primary caregivers and their family members. Lag sequential analyses and repetitive sequence analyses were conducted on observational data to determine the effects of joint problem solving, joint illness talk, and competing problem solving/illness talk on caregiver depression. The findings indicate that caregivers who compete with family members about the focus of the communication were more depressed. In contrast, caregivers were less depressed when they talked jointly with family members about the illness. Communication about joint problem solving and joint illness talk were also strongly related in these families. Possible explanations for these findings and implications for family therapy and future research are discussed.

Acknowledgements

Many individuals and families have deeply touched my life. I am appreciative of those who have shared their stories of struggle, resilience, and competence and who have demonstrated many ways of being a family. I am especially grateful for the Speice, Ewiak, and Engist families who have shown me the beauty and wisdom of aging, among many other gifts. In particular, my parents have supported this work with care, hope, and immense love.

My committee members all contributed to this research. Rosemary Blieszner bridged the mountainous distance with caring attentiveness over e-mail. I thank her for her cheerful guidance and editing finesse. Cleve Shields patiently brought me along in the quantitative journey and somehow managed my anxiety all the while. It has been a pleasure to work with both of them as co-chairs. I also appreciate the contributions of Jay Mancini, Bud Protinsky, and Joe Maxwell who joined in the creation of this work and supported its completion. I have learned much from this process.

In August 1994, I arrived at the Family Medicine Center with much energy and enthusiasm. Many people helped me to survive the roller-coaster year. The Mental Health Services Team in various ways gave me enormous encouragement to complete this research, despite the clinical challenges.

Thanks to Susan McDaniel, Dave Seaburn, Nancy Ruddy, Sally Rousseau, Clark Christensen, Jeff Harp, Tom Campbell and to Barbara Gawinski, in particular, for mentoring and caring "above the call". I could not have accomplished this without their support.

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Chapter I

Introduction

The challenge of managing family life with a debilitating chronic illness such as Alzheimer's Disease (AD) is monumental. The family is confronted with adjusting to the patient's chronic and progressive cognitive declines and behavioral changes amidst great uncertainty about new caregiving demands and the future quality of the relationship with the AD patient (Blieszner & Shifflett, 1990). The illness experience of AD includes substantial physical, emotional, and relational demands on all family members. The primary caregiver often feels particularly burdened (Schultz, Visintainer, & Williamson, 1990).

This study examined the relationship between family communication patterns and caregiver depression during the middle phase of AD. The patients and families who participated in this study were several years post-diagnosis of AD, and were considered to be in the middle phase of the illness. Their experience of this debilitating illness was expected to be very different from families that have recently received a diagnosis of AD or who are preparing for imminent death. The adjustment tasks during the many months and years of the middle phase are significantly different from those

required immediately following diagnosis or during bereavement (Rolland, 1984). During the "long haul" of the middle phase of a chronic illness, families often face several more years of demands that may threaten their developmental needs to attend to other tasks beyond caregiving (Rolland, 1987). Therefore, it is important for caregivers and families to address aspects of life other than the illness.

There is little literature on directly observed family communication patterns and their relationship to caregiver functioning. Some researchers have studied the relationship between expressed emotion in family communication and the well-being of caregivers of AD patients (Bledin, MacCarthy, Kuipers, & Woods, 1990; Gilhooly & Whittick, 1989; Niederehe, 1990; Orford, O'Reilly, & Goonatilleke, 1987). However, most of the literature has used self-report measures exclusively or focused on the early phase of AD and caregiving. The purpose of the present study was to examine empirically the relationships among family communication about the illness experience, family problem solving, and primary caregiver depression during the middle phase of AD. The results of this investigation have theoretical implications for understanding family communication and caregiver health status during the middle phase of a chronic illness. Clinical implications for

medical family therapists in terms of assessment of middle-phase family functioning and possible interventions into communication patterns to be enhanced or changed are also presented.

Chapter II

Literature Review

Phases of Chronic Illness

Scholars have conceptualized long-term serious illness as having three phases that patients and families undergo (Rolland, 1984; Reiss & Kaplan De-Nour, 1989). From a biomedical perspective, the timeline captures the moments from the first hints of disease, through diagnosis, treatment course, and death. More importantly, the illness life cycle includes the psychosocial aspects of the patient and family's experience of the illness. The tasks required of a family during each phase, broadly termed early, middle, and late, will be described in the next section.

The early phase of chronic illness begins with the onset of symptoms, or the presence of pathology detected in a routine examination. During this "acute" (Reiss & Kaplan De-Nour, 1989) or "crisis" (Rolland, 1984) phase, the family's focus is on obtaining an accurate diagnosis and an expected prognosis for the patient, as well as establishing a treatment regimen.

The middle phase of a chronic illness is often considered the "long haul" (Rolland, 1984). During this phase, the focus moves to long-term

maintenance in which patient care becomes more routine (Reiss & Kaplan De-Nour, 1989).

In the late phase, the family begins to acknowledge the inevitability of the patient's death. This terminal phase begins with the recognition of impending death and continues through the death and the mourning period (Rolland, 1984; Reiss & Kaplan De-Nour, 1989).

Family Communication Patterns

Families develop meaning systems about the illness that enable members to "make sense of" the illness (Kleinman, 1988). The ways in which family members communicate with each other may support the development of adaptive meaning systems. Maintaining communication enables family members to share their unique stories of the illness, recognizing that individual and family stories will change over the illness course (McDaniel, Hepworth, & Doherty, 1992). Family members who are able to communicate with each other by sharing illness stories and addressing caregiving tasks may be demonstrating the instrumental and affective aspects of healthy problemsolving (Epstein, Bishop, Ryan, Miller, & Keitner, 1993).

Characteristics of Alzheimer's Disease

The following four characteristics influence the experience of AD for the

patient and family: onset, course, outcome, and degree of incapacitation (Rolland, 1984). Alzheimer's disease is a chronic illness, with a gradual onset of symptoms, that includes cognitive declines and behavioral changes. The course is progressive, with increasing caregiving demands over time and no relief from symptoms. Alzheimer's disease shortens the life span of older adults, and can be fatal if another medical condition does not end life first.

Some of the expected declines include forgetfulness, agitation, personality changes, the need for increased supervision of daily activities -- dressing, feeding, bathing -- incontinence, nighttime wandering, and inappropriate social and sexual behaviors (Baumgarten, 1989; Cole, Griffin, & Ruiz, 1986; Reese, Gross, Smalley, & Messer, 1994). The results of the cognitive incapacitation are severe and, together with the progressive course, are the most burdensome aspects for families.

Family Tasks During the Phases of Alzheimer's Disease

The management of AD can contribute increased amounts of stress to all family members. The entire family system must engage in effective coping strategies in order to maintain a level of functioning despite the illness, day-to-day responsibilities, and other family developmental needs. Rolland (1987) suggested that one of the key goals in adapting to illness within the

family is to have members retain or regain some sense of autonomy from the illness in order to meet their own developmental needs.

The family must accomplish specific tasks if members are to cope successfully with the illness experience. Rolland (1994) highlights that "at each stage of a progressive illness, such as AD, the family needs to organize itself to deal with a particular level of disability and degree of uncertainty" (p. 25). A family's sense of "mastery" (Rolland, 1987) is related to its ability to "put the illness in its place" (Gonzalez, Steinglass, & Reiss, 1989) by accomplishing a series of different tasks at each phase.

In the early phase, the family is required to demonstrate "coordination" (Reiss, 1981; Reiss & Kaplan De-Nour, 1989) by supporting each other during the crises of identifying symptoms and pursuing the diagnosis of AD. This early phase is characterized by behavioral changes in the patient that are erratic and subtle (Garwick, Detzner, & Boss, 1994), and that are especially perplexing because the patient appears physically healthy (King, Bonacci, & Wynne, 1990). Garwick and colleagues (1994) described four themes that families in the early phase face: "(a) their awareness that something was 'wrong', (b) the uncertain nature of the diagnosis, (c) excluding a family member, and (d) the ambiguous nature of family life with 'it' (Alzheimer's

disease)" (p. 333). Families are called upon to grieve the loss of family identity and the person they knew before she or he developed AD (Rolland, 1984).

As family members come to understand the diagnosis of AD, they begin the process of establishing early caregiving roles and responsibilities. Often a primary caregiver is identified in the spouse, sibling, or adult child, usually a daughter. Family members exchange stories of symptoms, burdens, and uncertainty. The family is united through the process of talking about the illness and the primary caregiver finds an outlet for his or her concerns.

The acceptance of the AD diagnosis and the future prognosis signals the transition to the "long haul" of the middle phase. The family's task is to "try to live a normal life in abnormal conditions" (Rolland, 1987). The focus moves from identifying symptoms and accepting a diagnosis to long-term caregiving, including making plans for family home care or nursing home placement. The stress of caregiving demands and depletion of resources, both financial and emotional, can be exhausting (Rolland, 1994). The primary caregiver and family members must pursue creative solutions to caregiving problems amidst dwindling resources.

Successful completion of early-phase tasks sets the foundation for success in the middle phase of the disease process (Reiss & Kaplan De-Nour,

1989). Family communication patterns focused on solving caregiving problems may signify the caregivers' transition to the middle phase. Shields (1992) stated that "only when caregivers know that their family members understand them can they allow themselves to engage in problem solving that may change the situation" (p. 32).

During this middle phase, caregivers and family members who work together to solve problems can enhance their sense of efficacy or "agency" (McDaniel et al., 1992) by appropriately exerting what control they can have in uncertain times. Family members who have feelings of agency make it through the long haul of relentless caregiving by focusing more on the problems that they can solve and less on unproductive discussion of aspects of the disease that they cannot control.

After many months or years, when the family is faced with the inevitable death of the patient, they move into the late phase of AD caregiving. Often the caregiver and family begin to experience "anticipatory grief" as well as feelings of guilt at the relief they expect to feel when the patient dies (Rolland, 1994). This phase continues until the resolution of mourning by family members.

This study focused on family communication patterns during the middle phase of AD and their relationship to caregiver functioning. As discussed below, other research examining variables related to AD caregiving has highlighted the demands of caring for an AD patient, the potential health risks for the primary caregiver, and the influence of family relationships. One limitation of previous research is that investigators have not examined observationally family communication patterns in any detail nor linked the effects of these patterns to caregiver outcomes such as psychological well-being. Research on Caring for Alzheimer's Disease Patients

Families who are managing the tasks and demands of AD confront particular challenges, namely, coping with the patient's behavioral problems (Pearson, Teri, Wagner, Truax, & Logsdon, 1993), the progressive decrease in their ability to communicate with the patient due to the patient's cognitive loss (Williamson & Schulz, 1993), and the resulting decline in intimacy with the patient (Blieszner & Shifflett, 1990). Some caregivers receive relief from formal service providers (Zarit, Pearlin, & Schaie, 1993), but most rely on the support of family members to help with the adjustment and loss experiences and to reduce caregiver distress.

Research on Health Status of Caregivers

Many researchers have examined the relationships between the aspects of AD caregiving and caregiver depression. Schulz, Williamson, Morycz, and Biegel (1993) conducted a rare longitudinal study of AD caregiving and reported generally stable patterns of depression across the phases of caregiving. Increased caregiver depression has been positively related to patient's problematic behaviors (Pearson et al., 1993), the experience of burden (Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Zarit, Todd, & Zarit, 1986), and the perceived loss of control over the situational circumstances (Cohen & Eisdorfer, 1988). Similarly, Skaff and Pearlin (1992) found that the loss of self through role engulfment in caregiving is significantly positively related to caregiver depression. Morrissey, Becker, and Rubert (1990) reported complex variations in perceived negative impact related to employment status -- notably, homemakers' were more depressed than caregivers employed outside the home.

Alzheimer's disease caregiving has been demonstrated to take a toll on caregivers' physical health. Pruchno, Kleban, Michaels, and Dempsey (1990) found that increased depression predicted declines in perceived health status, particularly for female caregivers. Other researchers identified increased use of

medical providers and psychotropic medications (Brodaty & Hadzi-Pavlovic, 1990; George & Gwyther, 1986) or increases in blood pressure rates and declines in health behaviors (Moritz, Karl & Ostfeld, 1992) as a result of dementia caregiving.

Research on Family Relations of Caregivers

Caregivers' relationships with family members and perceptions of support from them are also related to caregiver well-being, depression, anger, and perceived burden. Scott, Roberto, and Hutton (1986) reported an inverse relationship between perceived family support and scores on Zarit's (1980) caregiver burden scale. Family interaction characterized by negative affect or overt disagreement is positively related to caregiver anger (Semple, 1992) and depression (Shields, 1992). Clearly, the effects of the quality of family relationships on AD caregivers can be significant, particularly in terms of caregiver functioning.

Propositions and Hypotheses

In this study, I focused on family communication patterns during the "long haul" middle phase of AD when families are burdened with the relentless illness and caregiving demands while also needing to focus on other family life tasks. In the early phase, caregivers and family members who cope

appropriately with the challenges of the early phase may be those who *focus on talking about the illness*, including the symptoms, medical treatments, and the eventual acceptance of the diagnosis of AD. In the middle phase, while still minimally oriented to aspects of the patient's illness, the family and primary caregiver begin to *negotiate the longer-term caregiving issues*. The focus should shift to joint problem solving, with only limited talk about the illness per se.

Given the illness phases and the family tasks thought to be associated with each phase, I propose three patterns of family communication during the middle phase. These patterns highlight the problem solving, illness talk, and emotionally validating aspects of the caregiver and family interactions.

- 1. Joint Problem Solving caregivers and families focus on solving problems related to caregiving issues and exchanging emotional validation for problem solving.
- 2. Competing Problem Solving/Illness Talk caregivers talk about the illness while family members talk about problem solving or are emotionally invalidating of caregivers' illness talk.
- 3. Joint Illness Talk caregivers and families persistently talk about their illness experience, generally in ways that are emotionally validating to each other.

Family communication patterns and the effects on caregiver depression during the middle phase of AD were examined in this study. Caregivers and family members who had moved to the middle phase were expected to focus on problem solving with only limited talk about the illness. The following hypotheses demonstrate the expected relationships between the examined family communication patterns and caregivers' reports of depression. The explanation of how the family communication patterns variables were operationalized is presented in the next chapter.

H1: The greater the competing problem solving/illness talk, the higher the caregiver depression.

H2: The greater the focus on joint problem solving, the lower the caregiver depression.

H3: The greater the joint illness talk, the higher the caregiver depression.

H4: The greater the joint illness talk, the lower the caregiver depression as compared to competing problem solving/illness talk, but the higher the caregiver depression as compared to joint problem solving.

Chapter III

Methodology

In this chapter I will present the research methodology including sample identification, procedures for obtaining data, measures used, and data coding that was conducted. A secondary data source provided by The University of Rochester (NY) School of Medicine and Dentistry, Department of Family Medicine was used. The original study was approved by the University of Rochester Research Review Board and this current study was approved by the Virginia Polytechnic Institute and State University Institutional Review Board (see Appendix C). The data set was collected and is administered by Cleveland G. Shields, Ph.D., Associate Director of Family Research. The characteristics of the original study (Shields, 1992) and the analyses for the current research follow.

Participants

Caregivers of middle-phase AD patients involved in a respite care program were recruited. Caregivers living with the patient and extended family members were invited to participate. The demographic characteristics of the AD caregivers are presented in Appendix A. The patients averaged over 76 years of age, were predominantly male and experienced significant cognitive

impairment as demonstrated by a mean Mini-Mental State score of 15.4 out of a maximum 30 (Folstein, Folstein, & McHugh, 1975). Based on the conventional interpretation that a score above 17 indicates mild impairment and a score above 24 indicates no impairment, the mean for these patients falls within the severe impairment range (Tombaugh & McIntyre, 1992). The primary caregivers were largely female, most often the spouse of the patient, and averaged over 60 years of age. The family members who participated included adult children and spouses, siblings, grandchildren and cousins (average number of participants per family = 2.4, range = 1 to 5).

<u>Procedures</u>

The research team scheduled 2-hour home visits with each patient's primary caregiver and family members. The identified caregiver and participating family members completed a self-report measure of depression, the indicator of psychological well-being used in this study. In addition, they participated in a family interaction task that was videotaped. All participants provided consent for taking part in all aspects of the study.

Depression Measure

During the home visit, the primary caregiver completed a lengthy self-report questionnaire that included a scale to assess perceived caregiver

depression. The Center for Epidemiological Studies - Depression Scale (CES-D) was developed for use in assessing depressive symptoms in epidemiological studies in the general population (Radloff, 1977). The 20 item scale includes items such as "I was bothered by things that don't usually bother me", "I felt sad", and "My sleep was restless" (Radloff, 1977). According to Radloff (1977), the split-half reliability is approximately .85 in the general population group tested, and higher in the patient sample. Discriminant validity between patient and general population groups was indicated by clinical and self-report criteria. The CES-D has been shown to be reliable in studies with older adults (Radloff & Teri, 1986).

Family Interaction Task

The research assistant led the caregiver and family in a videotaped, two part, family interaction task. In the first part of the task, the research assistant helped the family to reach consensus on a caregiving problem they wanted to solve; this took approximately 10 minutes. Then the research assistant instructed the family to focus on problem solving and left the room. Families worked on this activity for about 10 minutes. Conversation during the second, problem-solving stage, of the interaction task provided the data used in the present analyses.

Data Coding

The Codebook for Marital and Family Interaction (COMFI) coding scheme developed by Notarius, Pellegrini, and Martin (1991) provided the basis for coding the videotapes from the problem-solving activity. Shields and colleagues adapted the coding system to include an additional illness code. Two consecutive pages, approximately 10%, of each transcript were randomly chosen and reviewed for reliability. The data were coded by Sherry Wahlen, MD; the reliability coder was Sally Rousseau, MSW. Cohen's kappa of .7160 was obtained on the selected transcripts. This is considered within the "good" reliability range of .60 to .75; scores between .40 and .60 are rated as "fair" reliability and scores above .75 are considered "excellent" reliability (Bakeman & Gottman, 1986; Fleiss, 1981).

Table 1 presents a summary of the specific variables studied and the communication patterns between caregivers and family members that the variables represent. The codes used to identify the conversational statements -- problem-solving facilitation, emotional validation, emotional invalidation, and illness talk -- were adapted from The Codebook for Marital and Family Interaction (COMFI, Notarius, Pellegrini, & Martin, 1991). In general, statements that encouraged the problem-solving process were coded as

Table 1

Family Communication Patterns

Family Communication Patterns	Who (Said What)	To Whom (Response)
	C (PSF)	F (PSF)
Joint Problem	C (PSF)	F (EMV)
Solving	F (PSF)	C (PSF)
	F (PSF)	C (EMV)
	C (IT)	F (PSF)
Competing Problem	C (IT)	F (EMI)
Solving/Illness Talk	F (PSF)	C (IT)
Taik	F (PSF)	C (EMI)
	C (IT)	F (IT)
Joint Illness Talk	C (IT)	F (EMV)
	F (IT)	C (IT)
	F (IT)	C (EMV)

Note. C=caregiver, F=family member, PSF=problem solving facilitation, IT=illness talk, EMV=emotional validation, EMI=emotional invalidation.

problem-solving facilitation (PSF) and statements that referred to the AD patient or illness experience were coded as illness talk (IT). Positive statements and negative statements were coded as emotional validation (EMV) and emotional invalidation (EMI) respectively.

Chapter IV

Results

Data Preparation

Twenty-nine participant families had complete data, including caregiver depression (CES-D) and family problem-solving task videotapes. Missing data on individual items on the CES-D questionnaire were calculated by using the mean score of the completed items on the caregiver's questionnaire to estimate the missing items. The mean score on the CES-D was 34.9 with a range of 20 to 55, and a standard deviation of 9.86. The mean CES-D score of caregivers in this study is substantially above the score of 16 that was established to indicate a diagnosis of depression (Radloff, 1977). Although Radloff did not distinguish levels of depression, her research in a psychiatric population resulted in a mean score of 39.11 (Radloff, 1977).

The sequential analysis of this study was conducted according to the protocol presented in Appendix B (Shields, Watts, & Cox, 1995a). The text from the transcripts of the videotaped family interaction tasks was broken down into single thought units and assigned COMFI codes (Notarius, Pellegrini, & Martin, 1991). Sequences of two thought units were analyzed to determine their conditional probability -- the probability that a particular

sequence would occur given the first spoken code. Zscores were calculated for sequential probabilities. Zscores were calculated because they are considered to be more stable indicators of the strength of sequential relationships (Bakeman & Gottman, 1986). The Zscores represent a relationship to the chance occurrence of the sequence -- a positive Zscore indicates that a particular sequence occurred more often than expected by chance and a negative Zscore indicates that the sequence occurred less often than expected by chance (Gottman, 1979).

The lag sequential analysis presented here is similar to that used by Gottman (1979) to study marital interaction. This sequential analysis provides statistical comparisons of the probabilities of communication interactions between two people rather than just simple frequencies of one participant's coded thought units.

This results section is organized into the following three parts: (a)
Initial Analyses; (b)Lag Sequential Analyses; and (c) Sequence Repetition
Analyses. The hypothesized relationships between caregiver and family
communication and caregiver depression will be examined.

Initial Analyses

The initial steps of preparing the coded data for lag sequential analyses

included calculating simple frequencies and the probabilities of particular codes occurring. Table 2 contains the means, standard deviations, and correlations with caregiver depression for the individual communication codes. These results are presented for descriptive purposes. The probabilities indicate the percentage of occurrence of a particular code in relationship to all codes spoken. Table 2 shows that problem-solving talk occurred most frequently and with the highest probability, the illness talk occurred less frequently and with lower probability, and other variables occurred even less frequently. None of the individual probability codes were significantly correlated with caregiver depression at the p<.05 level.

Lag Sequential Analysis

Lag sequential analysis computes statistics for two or more event sequences, such as coded thought units. Statistics are computed for either the next occurring code (Lag 1), skipping a code (Lag 2), skipping two codes (Lag 3), or skipping additional codes (Lag 4 and beyond) (Sackett, 1977; Bakeman & Gottman, 1986). For this study, only Lag 1 sequences -- speaker (spoke) > to whom (responded) at the next occurring speech -- were examined. Bakeman and Gottman (1986) suggested that exploratory studies initially analyze only two event sequences and reduce the number of coded sequential probabilities

Table 2

Means, Standard Deviations (SD), and Correlations (r) of Individual

Communication Codes with Caregiver Depression

Variable ^a	Frequency Mean(SD)	Probability Mean(SD)	r ^b
C(PSF)	7.76(4.8)	0.13 (0.08)	.29
F(PSF)	8.72(5.15)	0.14(0.08)	.14
C(EMV)	0.28(0.96)	0.00(0.01)	24
F(EMV)	0.86(0.86)	0.02(0.02)	.34
C(IT)	2.59(3.51)	0.03(0.05)	26
F(IT)	2.07(3.44)	0.03(0.04)	33
C(EMI)	1.79(1.99)	0.03(0.03)	.11
F(EMI)	1.97(1.97)	0.03(0.03)	11

Note. Only selected codes of caregivers and family members related to this analysis are included in this table. Patient codes and other codes are not presented, which is the reason the probabilities do not sum to 100%.

^a C=caregiver, F=family member, PSF=problem solving facilitation, IT=illness talk, EMV=emotional validation, EMI=emotional invalidation.

^b None of the above codes were correlated with caregiver depression (CES-D) at p<.05.

used in order to reduce the possibility of error. Type I error would result in the interpretation of sequences as significant when they are not.

In this study, the number of sequential codes was reduced from the 12 originally proposed to 8 used in the lag sequential analysis. The four that were not included (family problem solving followed by caregiver emotional validation; caregiver illness talk followed by family emotional invalidation; caregiver illness talk followed by family emotional validation; and family illness talk followed by caregiver emotional validation) were dropped because they occurred in fewer than half of the interviews. One other step was performed prior to beginning the sequential analysis; four of the Zscores of sequential probabilities were transformed because they had non-normal (skewed) distributions. The extreme scores were transformed by taking the square root of (Zscore + x), where x was used to make a negative Zscore positive for the square root calculation (Tabachnick & Fidell, 1983).

Table 3 summarizes the means and standard deviations for the frequencies, probabilities, and calculated Zscores, as well as Zscore correlations with caregiver depression for the eight retained sequences. Notice that of the eight caregiver and family member sequences, only the sequence of caregivers responding with illness talk to family members' problem solving facilitation

Table 3

Means, Standard Deviations (SD), and Correlations (r) of Lag Sequences with Caregiver Depression

Sequential	Sequential	Frequency	Probability	Zscore	ı
Category	Variable	Mean(SD)	Mean(SD)	Mean(SD)	
	C(PSF)>F(PSF)	3.83(3.23)	0.47(0.29)	2.89(1.95)	10
Joint Problem Solving	C(PSF)>F(EMV	0.28(0.53)	0.06(0.13)	1.56(0.41) ^b	07
0	F(PSF)>C(PSF)	3.31(2.35)	0.42(0.27)	2.58(1.57)	3
Competing	C(IT)>F(PSF)	0.31(0.6)	0.09(0.22)	$0.09(0.22)$ $1.75(0.34)^b$.25
Problem Solving/ Illness Talk	F(PSF)>C(IT)	0.17(0.6)	0.02(0.06)	$0.02(0.06)$ $1.33(0.27)^b$.40*
	F(PSF)>C(EMI)	0.76(0.83)	0.10(0.11)	1.21(1.57)	06
Joint	C(IT)>F(IT)	0.86(1.75)	0.86(1.75) 0.16(0.26)	1.18(1.90)	25
Illness Talk	F(IT)>C(IT)	1.07(2.22)	$1.07(2.22) \mid 0.20(0.37) \mid 1.76(0.66)^{b}$	1.76(0.66) ^b	33

^a C=caregiver, F=family member, PSF=problem-solving facilitation, IT=illness talk, EMV=emotional validation, EMI=emotional invalidation.

^b Zscore was transformed.

* p < .05.

statements is significantly related to caregiver depression (r=.40, p<.05). This may mean that the caregivers who continue to talk about the illness after family members initiate problem-solving talk are more depressed. It is also possible that caregivers who are more depressed stay focused on talking about the illness even when family members have changed the subject. Based upon the results of this analysis, the hypothesis that there is a difference in caregiver depression as related to the competing problem solving/illness talk communication between caregivers and family members is supported.

Within the joint problem-solving category, the sequence of caregivers responding with problem solving facilitation to the family members' problem solving talk had a negative, but not statistically significant, correlation with caregiver depression (r=-.27, p<.15). Therefore, the second hypothesis concerning the connection between caregiver depression and joint problem-solving communication was not supported by these data. Similarly, the third hypothesis was not supported; the correlation between caregiver depression and joint illness talk initiated by family members was not statistically significant (r=-.33, p<.09).

In contrast, several of the communication sequences in the two joint categories (illness talk and problem solving) were highly inter-correlated (see

Table 4). Joint problem solving initiated by the family members (see column c) and illness talk initiated by caregivers (d) or family members (e) were closely related. Similarly, caregivers' initiation of joint problem solving (a) was also strongly related to caregiver initiated illness talk (d) and family members' initiation of illness talk (e). This covarying cluster of variables suggests that there might be an underlying factor such as "cooperative communication" influencing the relationships among the sequences.

Finally, Table 5 shows the results of a forward Stepwise regression of the sequences with the highest correlations from each of the three categories (see Table 3) regressed on caregiver depression. After entering the three sequence Zscores (competing family problem solving followed by caregiver illness talk, joint illness talk initiated by family members, and joint problem solving initiated by family members), only the competing sequence was statistically significant (F=5.0, p<.05). This sequence of family problem solving followed by caregiver illness talk accounts for 15% of the variance in caregiver depression.

The analyses of the lag sequences yielded several findings related to the hypotheses. The data supported the first hypothesis, indicating that the greater the tendency of caregiving families to engage in a competing problem

Table 4

<u>Correlations Between Joint Problem Solving and Illness Talk Lag Sequences</u>

Sequential Category	Sequential Variable ^a	Joint Problem Solving			Joint Illness Talk	
		(a)	(b)	(c)	(d)	(e)
Joint Problem Solving	(a)C(PSF)> F(PSF)	1.0				
	(b)C(PSF)> F(EMV)	35	1.0			
	(c)F(PSF)> C(PSF)	.39 *	21	1.0		
Joint Illness Talk	(d)C(IT)> F(IT)	.40	11	.51 **	1.0	
	(e)F(IT)> C(IT)	.51 **	07	.49 **	.18	1.0

^a C=caregiver, F=family member, PSF=problem solving facilitation, IT=illness talk, EMV=emotional validation, EMI=emotional invalidation. p<.05. **p<.01.

Table 5

Stepwise Regression of Lag Sequences on Caregiver Depression

Sequential	Parameter	'n	Partial	Model	ŗ	Prob>
Variable	Estimate	5E	KZ	K2	F	ŀ
F(PSF) > C(IT)	14.427	6.452	.156	.156	5.00	0.034

Note. None of the other lag sequences met the tolerance requirement for entry into the regression model at the .1500 level.

^a F=family member, C=caregiver, PSF=problem-solving facilitation, IT=illness

talk.

^b Zscore was transformed.

solving/illness talk style of communication, the more likely the caregiver is to be depressed. The second hypothesis was not supported; joint problem solving was not related to caregiver depression. The third hypothesis also was not supported; joint illness talk was not related to caregiver depression. The fourth hypothesis was not supported; there was no evidence that joint problem solving or joint illness talk were related to caregiver depression. However, a strong relationship was found between the two joint sequences, indicating that caregivers and family members who are able to jointly focus on illness talk may also cooperate on problem solving.

Sequence Repetition Analysis

Following the lag sequential analysis, sequence repetition analysis was used to conduct a more indepth investigation of illness talk and caregiver depression (Shields, Watts, & Cox, 1995 b). Sequence repetition analysis examines consecutively repeated sequences during an interaction task (see description of K-gramm analysis in Halweg & Goldstein, 1987; Halweg & Jacobson, 1984).

Sequence repetition analysis is similar to the lag sequential analysis conducted previously. However, it examines the length of repeated sequences (i.e. how many times the same sequence is repeated). These repeated

sequences represent sustained discussion on the same topic. An example of a repetitive sequence with a length of 3 is:

$$CIT > FIT \longrightarrow CIT > FIT \longrightarrow CIT > FIT \longrightarrow CIT > FIT$$

$$(0)$$

$$(1)$$

$$(2)$$

$$(3)$$

(Where, CIT = caregiver talking about the illness; FIT = family member talking about the illness; 0 = original sequence; 1 = first consecutive repetition; 2 = second consecutive repetition; 3 = third consecutive repetition.)

For analysis purposes, the second sequence (the first repetition) is counted as 1. Therefore, although x=1, there have been two exchanges of the same sequence of communication.

Two types of repetitive sequences were analyzed to examine further the effects of illness talk between caregivers and family members on caregiver depression -- joint illness talk and competing illness talk. The illness talk (IT) variable represents sustained illness talk (IT) or emotionally validating (EMV) replies to previous illness talk. The competing illness talk (CP) variable was developed as a compilation of all codes other than the illness talk or emotional validation codes. Competing illness talk represents non-sustained or competitive replies to illness talk, such as emotional invalidation(EMI),

problem solving facilitation (PSF) or problem solving inhibition(PSI). The specific ways in which caregivers and family members competed were not as critical to the analysis as was the fact that they were competing. In contrast to the lag sequential analyses, which examined the probabilities of specific codes following another code, sequence repetition analyses examined the overall length of sustained sequences.

Table 6 shows the descriptive statistics of the repeated sequences including the maximum length and the correlations with caregiver depression. The maximum length represents the longest repetition of a sequence (note: the maximum lengths of 6 repeated sequences for joint illness talk actually represent 7 communication exchanges between caregivers and family members or 14 statements of illness talk). The minimum length of all the sequences shown was 0, indicating that there were no consecutive repetitions of the selected sequences in those family conversations. The descriptive statistics indicate that repeated joint illness talk sequences initiated by caregivers or family members once initiated, tended to continue longer than competing illness talk sequences.

Table 6

Means, Standard Deviations (SD), and Correlations (r) of Sequence Repetitions with Caregiver Depression

Sequence Repetition Analysis	Variable ^a	Mean(SD)	Maximum Length	r
_	C(CP)>F(IT)	1.07(1.28)	4	.42*
Competing Illness Talk	F(IT)>C(CP)	1.34(1.32)	4	.44*
	F(CP)>C(IT)	1.17(1.54)	5	20
	C(IT)>F(CP)	1.17(1.47)	5	17
Joint	C(IT)>F(IT)	1.86(2.03)	6	29
Illness Talk	F(IT)>C(IT)	1.90(1.86)	6	44*

^a C=caregiver, F=family member, CP=competing talk, IT=illness talk.

^{*}p<.05.

Two of the competing sequence repetitions were positively correlated with caregiver depression -- caregivers initiating competing talk followed by family members' illness talk and caregivers responding with competing talk to family members' initiation of illness talk. These two repetitive sequences suggest that in families in which caregivers and family members do not have the same focus of communication, caregivers are more depressed. The implications of caregivers maintaining competing talk when conversing with family members focused on the illness will be discussed in the next chapter. The repeated sequence of family members and caregivers jointly talking about the illness was negatively correlated with caregiver depression. Contrary to the competing illness talk pattern, caregivers are less depressed when they and their family members jointly talked about the illness.

As expected, the reciprocal repetitive sequences (Table 7) of caregivers competing with family members' illness talk, family members competing with caregivers' illness talk, and joint illness talk were all significantly correlated. Also, joint illness talk was highly correlated with family members' competing responses to caregivers' illness talk.

A test of multicollinearity determined that although several of the repeated sequences were significantly correlated with each other, they did not

Table 7 Correlations Between Competing Illness Talk and Joint Illness Talk Sequence Repetitions

Sequence Repetition	Variable ^a	Competing Illness Talk				Joint Illness Talk	
Analysis		(a)	(b)	(c)	(d)	(e)	(f)
Competing Illness Talk	(a)C(CP)> F(IT)	1.0					
	(b)F(IT)> C(CP)	.71 ***	1.0				
	(c)F(CP)> C(IT)	22	.18	1.0			
	(d)C(IT)> F(CP)	31	.12	.84 ***	1.0		
Joint Illness Talk	(e)C(IT)> F(IT)	01	.15	.47 **	.42	1.0	
	(f)F(IT)> C(IT)	06	.09	.49 **	.51 **	.94 ***	1.0

 $[^]a$ C=caregiver, F=family member, CP=competing talk, IT=illness talk. *p < .05 . **p < .01. ***p < .0001.

cause a problem of multicollinearity in the regression model. Table 8 indicates that two repeated sequences -- family members initiating illness talk followed by competing talk or illness talk by caregivers -- accounted for 42% of the variance in caregiver depression.

In summary, the sequence repetition analysis suggested that caregivers who maintain a conversational focus with family members about the illness

Table 8

Stepwise Regression of Sequence Repetitions on Caregiver Depression

Sequence Repetition Variableª	Parameter Estimate	SE	Partial R2	Model R2	Ŧ	Prob> F
F(IT) > C(CP)	3.5918	1.1241	1912	.1912	.1912 6.3823	.0177
F(IT)>C(IT)	-2.5441	9962	.2279	.4191	10.199	.0037

Note. None of the other sequence repetition variables met the tolerance requirement for entry into the regression model at the .1500 level.

^a F=Family member, C=Caregiver, IT=Illness Talk, CP=Competing Talk.

report lower depression, whereas caregivers who compete with family members about the focus on the illness report higher depression. These results expand the lag sequential findings that caregivers whose immediate response competes with family members about the focus on problem solving or illness talk are more depressed than those who sustain a mutual conversational focus with their family members.

Chapter V

Discussion

Lag sequential analysis showed that competing problem solving/illness talk between caregivers and family members was positively related to caregiver depression. The results of the sequence repetition analysis demonstrated that competing illness talk was related to higher caregiver depression, whereas joint illness talk was related to lower caregiver depression. Unexpectedly, joint problem solving and joint illness talk were highly correlated with each other in the lag sequential analysis. These findings suggest two underlying communication processes -- cooperation and competition about illness talk. In the following section, I will discuss several possible meanings of the results by type of communication sequence.

Joint Problem Solving

The tendency of caregivers and family members to engage in joint problem-solving communication was not associated with the caregivers' level of depression. Such a sequence, however, correlated with the likelihood that caregivers and family members both discussed the illness itself. This finding suggests that caregivers and family members who are able to address the illness experience directly are also able to solve problems associated with having an

AD patient in the family. Problem-solving and affective communication are both important aspects of relationships (Fitzpatrick, 1988). One possible interpretation of these findings is that joint problem solving represents instrumental support and joint illness talk represents emotional support. Together these types of support represent critical expressions of family functioning (Epstein et al., 1993), and skills necessary to face the demands of caregiving.

<u>Ioint Illness Talk</u>

In families in which caregivers and family members talk together about the illness experience, caregivers report less depression as compared to caregivers who seem to compete with family members about the emphasis of the conversation. Possibly, the former caregivers feel emotionally supported by family members listening to their stories or by their family members also talking about the demands of the illness. Emotional support has previously been demonstrated to benefit AD caregivers (Scott et al., 1986; Zarit et al., 1980).

The relationship between joint illness talk and caregiver depression became evident in the sequence repetition analysis, which examined the repetition of communication sequences within a conversation. A key factor

in this finding may be the ability of the family members to maintain the focus with the caregiver -- to hear and share stories -- rather than change the emphasis to problem solving. Perhaps the family members perceived the need to be attentive to the caregiver in this way, or the family members themselves needed to share their experience of the illness more.

Competing Talk

Two different types of competing communication that were significantly correlated with caregiver depression will be discussed below. In the initial lag sequential analysis, caregivers who were more likely to respond with illness talk to family members' problem solving talk reported higher depression. In the sequence repetition analysis, caregivers competing with the initiation of illness talk by family members reported higher depression. Overall, disagreements about the focus of the conversation are related to caregivers' increased depressive symptoms.

Competing Problem Solving/Illness Talk

Caregivers who continued to talk about the illness after family members initiated problem-solving talk may be more depressed because they felt their family members did not really listen to what they were saying. As suggested in the previous chapter, it is also probable that the more depressed caregivers stay

focused on the illness, and are not able to talk with family members about other things. At the same time, family members may be determined to help the caregiver "get over it" by solving some of the caregiving problems. Family members may have become frustrated with attempts to help the caregiver, and caregivers may feel less supported (Coyne, 1976; Coyne, 1990). Due to the nature of this cross-sectional study, it is not possible to determine a causal relationship between caregiver depression and competing talk.

Competing Illness Talk

The results of the repetitive sequence analysis showed that caregivers who competed with family members' initiation of illness talk were more depressed than caregivers who talked together with family members about the illness. At first, this appears contrary to previous findings that less depressed caregivers talk with family members about the illness. Why would these caregivers not want to talk with their families about the illness? It is possible that those caregivers who are feeling "stuck" in their depression may be unable to listen to family members talk about their own difficulties with the illness experience. Or they may perceive that one more burden is being placed on them -- to listen to the struggles of family members -- when they already feel overburdened by the demands of caring for the patient. The sense of being

overwhelmed when caregivers become engulfed in their roles may contribute to the inability to listen to others' challenges (Skaff & Pearlin, 1992).

Although there are multiple interpretations for the relationships between cooperative or competing talk and caregiver depression, clearly the ways that families talk about the illness can influence the experience of the illness. The theoretical and clinical implications of this study's findings will be explored below.

Theoretical Implications

The results of this study have implications for exploring family communication about the illness in the middle phase of AD. In addition, the findings may contribute to the understanding of the effects of family illness talk on caregiver depression.

Family Communication During the Middle Phase

Some authors (Reiss & Kaplan De-Nour, 1989) have suggested that the successful resolution of the tasks of one phase of a chronic illness is necessary before a family can move on to the next phase and to attain "mastery" (Rolland, 1987) over it. I originally presumed that there would be less illness talk in the middle phase, when caregivers and family members need to address aspects of life other than the illness. It was expected that caregivers who

reported less depression would focus more on problem solving with their family members. There may be less middle-phase illness talk in families with less depressed caregivers as compared to the early phase; however, a longitudinal study is required to determine these relationships. The findings of this study suggest that the process of talking about the illness may be ongoing, rather than ending in or only occurring during the early phase.

The progressive nature of AD, with its additional cognitive and behavioral declines over time, may suggest a need for continued talk about the illness. The experience of AD and other progressive chronic conditions may differ from the experience of chronic illnesses that have a constant or episodic course (Rolland, 1984). Caregivers and family members may persist in talking about the illness because they continually face new challenges with the patient. Ongoing illness talk may also help caregivers and family members grieve the pre-illness identity of the patient and family.

In addition, the results indicated that caregivers who talk jointly with family members about the illness also problem solve with them. Perhaps these caregivers and family members communicate about other life tasks in similar ways. Therefore, less depressed caregivers may be in families in which the illness, caregiving issues, and other developmental tasks are all addressed.

Rather than assuming that continued talk about the illness implies a lack of "mastery" of the illness, this pattern may imply that caregivers and family members are capable of accomplishing other developmental tasks as well.

Rolland (1987) contends that the principle task of adjusting to a chronic illness is creating a meaning system about the illness that implies a sense of competency. Meaning systems are created through sharing stories (Boss, 1993) or illness narratives (Kleinman, 1988). According to the present findings, sharing illness stories with family members appears to benefit caregivers. In addition, caregivers and family members who discuss the illness also problem solve together. In this way, families increase their experience of "agency" and "communion" -- feeling some sense of control about whatever decisions over which one can have control and feeling supported by others who care (McDaniel et al., 1992). These aspects complement each other through attention to instrumental and emotional needs.

Effects of Family Illness Talk on Caregiver Depression

The results indicated that caregivers who compete with family members about illness talk have higher depression than caregivers who cooperate with family members about the conversational focus. Although causal relationships cannot be suggested due to the cross-sectional nature of this study, the

findings show that caregiver depression and competition about family communication co-occur. This co-occurrence supports the interactional view of depression (Coyne, 1976; Coyne, 1990) that depressed caregivers and their family members mutually influence each other. Families may find it difficult to talk with a depressed caregiver and may become frustrated in their attempts to help. Caregivers may feel less supported by family members who become frustrated with them. The competition over the focus of communication may perpetuate these interactions.

Family communication was demonstrated to be related to caregiver depression during the middle phase of AD. These findings suggest several implications for the practice of family therapy.

Clinical Implications

Many caregivers benefit from talking with their family members about the challenges of the illness experience. Family therapy can encourage this communication. Although family therapy has historically had a problem-solving focus (Seaburn, Landau-Stanton, & Horwitz, 1994), the results of this study show that caregivers whose families give them a chance to tell their stories are less depressed. Therapists should encourage joint talk about the demands and losses associated with AD. Additional information

about the illness can be provided in a psychoeducational format (Gonzalez et al., 1989) that may create common ground to initiate conversation. Medical family therapists (McDaniel et al., 1992) can use the illness focus as a useful way to build rapport with caregivers and family members.

Illness Storytelling

Through the sharing of stories, families create meaning systems about the illness (Boss, 1993) and develop illness narratives (Kleinman, 1988).

Family therapists can support families' abilities to "externalize" (White & Epston, 1990) the challenges of the illness. By "putting the illness in its place" (Gonzalez et al., 1989), the family may successfully attain some sense of "mastery" over the illness experience and be able to attend to other aspects of life (Rolland, 1987). Thus, families who are able to talk about the illness and rewrite more adaptive stories may pass along enhanced family stories (Seaburn, Lorenz, & Kaplan, 1992) or family identity (Steinglass, Bennett, Wolin, & Reiss, 1987) to future generations.

Another implication is that therapists should intervene in families' problematic "attempted solutions" (Watzlawick, Weakland, & Fisch, 1974). For example, family therapists can interrupt the rigid competing patterns of family members' repeated efforts to redirect conversations to address problem

solving with the positive intent of trying to be helpful to the caregiver. One approach to "doing something different" (deShazer, 1985) is to allow the focus of the talk to remain on the illness, as suggested above. Family therapists should look for opportunities to encourage family members when they already respond to caregivers with illness talk. The goal is to support the families' demonstrated abilities (Hudson O'Hanlon & Weiner-Davis, 1989).

Assessment of Family Communication

The results also have implications for assessment of family functioning during the middle phase of AD. Caregivers and family members who talk about the illness together had lower depression than caregivers in families with competitive communication sequences. As suggested by the interactional view of depression (Coyne, 1976; Coyne, 1990), caregivers and family members may reciprocally influence the experience of depression. Therefore, families with depressed caregivers may experience more difficulty adjusting to the illness. Assessing family communication to explore this interactional pattern may benefit caregivers and family members who are stuck in rigid ways of relating with each other and unable to interrupt the depressing and frustrating interactions.

Caregivers and family members who talked jointly about the illness also focused on problem solving. A family's abilities to address the affective and instrumental aspects of problem solving have been suggested to be an important indicator of family functioning (Epstein et al., 1993).

Even families who are generally well-functioning experience the strain of chronic illness, especially one as debilitating as AD. Family therapists are valuable resources to help families identify the normative stress associated with the demands of the illness. Families may benefit from therapeutic interventions aimed at encouraging joint discussions about the illness and interrupting competing communication. Family therapy can normalize the experience of adjusting to an illness by teaching families that the need to make sense out of the illness goes hand in hand with problem solving. These efforts may result in lowering caregiver depression, finding solutions to caregiving problems, adjusting to the illness experience, and creating an enhanced family identity. Further research to examine the implications of this exploratory study is needed.

<u>Limitations</u>

As discussed above, this study yielded important new information about the connections between communication patterns and caregiver depression. It is important, however, to acknowledge some limitations of the sample and design. First, a larger, more representative sample of caregiving families is needed to assess the generalizability of these findings to other groups. Second, the participants in this study were receiving respite care services from a community agency. How they compare to families not using respite care is unknown. Finally, the cross-sectional design of this investigation renders it exploratory. It is impossible to determine the causal direction of influence between communication patterns and caregiver depression. Nevertheless, the findings obtained from the present analyses suggest several important directions for future research.

Recommendations for Future Research

The present findings point to the need for expanded exploration of cooperative and competitive family communication patterns. Further research into the covariation of joint illness talk and joint problem solving as related to caregiver depression is warranted. Future studies using path analysis with a larger sample size should examine the relationships between the joint patterns and caregiver depression to determine the direct and indirect effects. Other outcome variables such as perceived health status and medical utilization should also be analyzed in addition to caregiver depression. It may be

determined that caregiver depression also has a mediating effect on perceived health status and medical utilization. As noted previously, a longitudinal approach would allow one to examine the causal relationships between family communication and caregiver depression.

Further research into the area of family communication and chronic illness should incorporate other chronic illness conditions such as cancer, diabetes, heart disease, lung disease, stroke, and possibly mental illness.

Variations in disease onset, course, outcome, and degree of incapacitation (Rolland, 1984) should be explored. It is likely that family communication and outcome variables may be influenced by various aspects of the illness.

Longitudinal studies of illness phases (Reiss & Kaplan De-Nour, 1989; Rolland, 1987) are recommended. Causal links between variables such as family communication and caregiver depression can then be identified, as well as more general effects of the illness course on caregiver and family functioning or health status. Research with chronic conditions other than AD may also incorporate the illness experience of the patient.

New research should examine more directly the influence of caregiver and family affect. Previous research has suggested that negative affect is predictive of marital distress (Gottman & Levenson, 1988). Little research has

been conducted to identify the effects of intergenerational affective processes.

In particular, there may be implications for caregiver or patient physical and mental health status related to family affect.

The discipline of family therapy has been criticized for failing to conduct empirical outcome studies measuring the efficacy of family therapy interventions (Shields, Wynne, McDaniel, & Gawinski, 1994). It would be useful to evaluate the therapeutic interventions of medical family therapists working with caregivers, family members, and patients managing chronic illness. Examining the effects of therapeutic interventions on caregiver depression, perceived health status, and medical utilization may have implications for the changing health care system.

In conclusion, new research is needed to examine further the effects of family communication during a chronic illness. This study suggests that cooperative and competitive communication within families is related to caregivers' reported depression. Medical family therapists who encourage joint talk about the illness support a context were families can develop adaptive illness stories that may benefit all members.

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Appendix A

Participant Demographics

Variable	Mean(n ^a)	SD	
Caregiver age	61.7	14.4	
Caregiver gender	(M=8) (F=21)		
Household Income	2.7	1.5	
1 <10,000	(3)		
2 10,000-19,999	(7)		
3 20,000-29,999	(8)		
4 30,000-49,999	(2)		
5 50,000 +	(3)		
Caregiver Education	4.3	2.1	
l Grade school	(3)		
2 HS graduate	(0)		
<u>College</u>			
3 Attended	(8)		
4 Graduate (2yr)	(5)		
5 Graduate (4yr)	(2)		

Grad School

6 Attended (7)

7 Masters (1)

8 Doctorate (3)

Relationship to Patient

Spouse (15)

Daughter (9)

Son (2)

Sister (1)

Other (2)

Other Family Members

Present with Caregiver 2.4

 $^{^{}a}$ n=29.

Appendix B

Technical Appendix: Sequential Analysis to Calculate

Family Communication Variables

1. The transcripts from the videotaped Family Interaction Task (FIT) are broken down into thought units and COMFI codes are applied. For example:

Who To Whom Said Code

C F "We sure could use some help (CIT)

taking care of dad at home"

[C=caregiver; F=family member; CIT=problem talk about caregiving issue.]

2. The coded data are then entered into a computer file.

Who To Whom Code

C F (CIT)

3. The individual codes are then collapsed into more general categories. For example:

Category Individual Codes

(PSF) (PT, CIT, PS, PC, AR)

4. Simple frequencies are calculated. For example, the number of times that a particular caregiver talked about the illness (IT) is 25.

- 5. Sequential frequencies are then calculated. For example, the number of times that a family member responded with a problem solving (PSF) statement to a particular caregiver's illness talk (IT) is 15.
- 6. Next, the probabilities of sequences are calculated. The probability of a sequence is the frequency of the sequence divided by the frequency of the first code in the sequence. For example, the sequential probability of the family member responding with emotional validation (EMV) to a caregiver's illness talk (IT) is equal to the frequency of this sequence [C(IT) --> F(EMV)] divided by the frequency of [C(IT)].
- 7. Z-scores of particular sequences are then calculated.

The formula for computing z-scores for sequential probabilities is as follows:

$$Z = \underbrace{FQ(\text{sequence-} FQ(\text{code } i) \ X \ FQ \ (\text{code } i+1)}_{\sqrt{[FQ(\text{code } i)][FQ(\text{code } i+1)][1-\text{Prob}(\text{code } i+1)][1-\text{code } i]}}$$
 Where, FQ=frequency; Prob=probability; code i=initial code in sequence; code i+1=second code in sequence.

Note. From Lag counts: A SAS program to compute lag sequential statistics. by C. G. Shields, A. Watts, & C. Cox, 1995, Unpublished manuscript, University of Rochester. Adapted by permission.

Appendix C Institutional Review Board Approvals



Office of the Associate Provost for Research 306 Burruss Hall Blacksburg, VA 24061-0244 (703) 231-9359 FAX: (703) 231-7522

MEMORANDUM

TO:

Jenny Speice, Rosemary Blieszner & Cleveland Shields

Family and Child Development

FROM:

Ernest R. Stout

Associate Provost for Research

DATE:

March 2, 1995

SUBJECT:

IRB EXPEDITED APPROVAL/"Research Evaluation and

Respite Care for Family Caregivers of Alzheimers Disease

Patients: A Pilot Study"

Ref. 95-091

I have reviewed your request to the IRB for the above referenced project. I concur with Dr. Bird that the experiments are of minimal risk to the human subjects who will participate and that appropriate safeguards have been taken.

This approval is valid for 12 months. If the involvement with human subjects is not complete within 12 months or there is a significant change in the protocol of the project, the project may be resubmitted for extension or approval.

On behalf of the Institutional Review Board for Research Involving Human Subjects, I have given your request expedited approval.

Best wishes.

ERS/php

c: Dr. Bird



Approval of Research

Date: 05,17,88 RSRB =: 3170

Principal Investigator. Shields, Cleveland G., Ph.D.

Project Title: Research Evaluation of Respite Care for Family Caregivers of Alzzeimer's Disease Patients: A Pilot Study.

This Board has reviewed the information you have submitted regarding the above application and has given APPROVAL*.

Additional Remarks:

Any modifications in the proposal as approved by this Board involving changes in the subjects of study, the means of obtaining informed consent, or in the risk to the subjects should be sent to the Board for re-evaluation by this Board.

Consent forms with patient/subject signatures must be kept in the principal investigator's files at all times. (Records must be retained at least 3 years after a project is completed :

If a drug is to be used in the study, the drug should be stored in the Pharmacy for dispensing and inventory control. Any adverse reaction to biologicals, drugs, radioisotopes or medical devices must be reported to the Research Subjects Review Board for evaluation. (This is in addition to any other agency to whom you would report adverse reactions.)

Adverse reactions reported by other investigators involving any substance used in this study should also be reported to the University of Rochester Research Subjects Review Board.

A PROGRESS REPORT WILL BE REQUIRED AT LEAST ANNUALLY.

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The Department of Health and Human Services has approved the University of Rochester Multiple Project Assurance (#M01357) in accordance with the Federal Regulations of Ntarch 8, 1983 and its Subparts B, C & D for the Protection of Human Subjects.

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Valerie Bartlett Executive Director

Complete Board listing on reverse side.

(The approval will be withdrawn if at any time the conditions and requirements of the RSRB are not met.)

05..0/88

Avenue L'Avenue Rochester, New York 14042 (716) 275-2388

Jenny Speice

Education

- Ph.D., 1995, Family and Child Development, Specialization in Marriage and Family Therapy, Virginia Polytechnic Institute and State University Blacksburg, VA
- M.S., 1991, Counseling Psychology, Gannon University, Erie, PA
- B.A., 1987, Arts & Humanities, Gannon University, Erie, PA

Professional Experience

Clinical Internships

- 8/94 to 8/95, Department of Family Medicine, University of Rochester
- 1/93 to 5/94, Center for Family Services, Virginia Polytechnic Institute and State University
- 8/91 to 12/91, Family Therapy Center, St. Vincent Hospital, Erie, PA

 <u>University Teaching</u>
- 8/94 to 8/95, Department of Family Medicine, University of Rochester
- 9/92 to 5/94, Department of Family and Child Development, Virginia Polytechnic Institute and State University

Recognition

1994 Graduate Student Award for Teaching Excellence, Department of
Family and Child Development, Virginia Polytechnic Institute and
State University

Professional Affiliations

3/93 to 5/95, American Association for Marriage and Family Therapy,
Student Member

1/95 to 5/95, Collaborative Family Health Care Coalition, Student/New Professionals Task Force

Jenny Speice

Birthdate: 8/30/66