

THE PENNSYLVANIA STATE UNIVERSITY
SCHREYER HONORS COLLEGE

DEPARTMENT OF HUMAN DEVELOPMENT AND FAMILY STUDIES

COMMUNICATION PROBLEMS BETWEEN CAREGIVERS AND INDIVIDUALS
WITH DEMENTIA: IMPLICATIONS FOR CAREGIVER WELL-BEING

JEANNA M. STIADLE
SPRING 2014

A thesis
submitted in partial fulfillment
of the requirements
for a baccalaureate degree in Communication Sciences and Disorders
with honors in Human Development and Family Studies

Reviewed and approved* by the following:

Dr. Steven H. Zarit
Head of the Department of Human Development and Family Studies
Thesis Supervisor

Dr. Lisa Gatzke-Kopp
Professor of Human Development and Family Studies
Honors Adviser

* Signatures are on file in the Schreyer Honors College.

ABSTRACT

Communication problems resulting from dementia have been extensively described by clinicians, but little research has examined how these problems affect family caregivers. As individuals with dementia (IWDs) experience decreasing communication capacity, caregivers may develop feelings of burden. This study investigates different aspects of communication behaviors and their effects on caregiver outcomes using cross-sectional and longitudinal analyses. I identified scales for positive, aggressive, and depressive communication to test them as predictors, and related them to caregiver outcomes: depression, anger, positive affect, and role overload. This research will pave the way for interventions to improve communication between IWDs and caregivers.

TABLE OF CONTENTS

List of Figures	iii
List of Tables	iv
Acknowledgements.....	v
Chapter 1 Introduction	1
Chapter 2 Current Study	15
Chapter 3 Design and Methods.....	17
Chapter 4 Results	30
Chapter 5 Discussion	37
BIBLIOGRAPHY	45

LIST OF FIGURES

Figure 1. Explanation of Attrition.....18

LIST OF TABLES

Table 1. Demographic Information. (Replace this with table caption above the table).....	20
Table 2. Factor Analysis: Rotated Component Matrix.....	22
Table 3. Multiple Linear Regression.....	32
Table 4 Multilevel Modeling (MLM) Results	36

ACKNOWLEDGEMENTS

For Grammy.

Chapter 1

Introduction

A woman named Valerie describes her most frightening encounters with her husband, Donald, as he struggles to communicate in the face of his severe dementia. In the following quote, she expresses that the communication disorder sometimes provides a catalyst for violence. “He’s attacked me three or four times. At first I thought he was trying to kill me, but he’s expressing his anger... There’s times I’ve wanted to hit him” (Aneshensel, 1995, p. 116). Researchers project that by 2050, there will be over 65 million cases of dementia worldwide (Katzman and Fox, 1999). While affected individuals themselves command a great deal of attention, research often neglects the syndrome’s severe impact on family caregivers of individuals with dementia.

Caregivers experience a multitude of problems regarding their relationships with Individuals With Dementia (IWDs) (Zarit, 1985). IWDs are typically older adults, who face physical limitations that create communication difficulties, which may include loss of hearing, decreased visual acuity, and increased reaction and processing time (Nussbaum, 2000). Individuals with a compromised ability to communicate, such as IWDs, may be less likely to receive help with communication that pertains to goals outside of simple wants and needs (Light, 1997; Blackstone, 1996) For older adults, this issue is particularly problematic, since their isolation inhibits their valued communication needs. In particular, this specific population requires both social closeness (communicating to develop and maintain social relationships) and information transfer

(sharing information with communication partners), but may experience difficulty achieving such needs, further alienating the group from others (Blackstone, 1996).

As a response to the frustration and stress associated with the inability to communicate effectively, an IWD may exhibit aggressive and/or depressive communicative behaviors. These problems typically upset family caregivers because they represent changes in the relationship with the IWD. Furthermore, additional issues such as caregiver burden, role overload, and depression may contribute to communication problems with the IWD (Germain, 2009). Since interactions between IWDs and caregivers are so strenuous, they likely affect caregiver well-being in a severely negative way.

Although many studies acknowledge communication struggles between IWDs and caregivers, few examine the emotional nature of these problems. This study analyzes the various types of communication behaviors exhibited by IWDs and the corresponding effects on caregiver burden and well-being. This project will benefit researchers because it proposes new, more dyad-focused communication intervention strategies for *both* the demographic of IWD's, as well as their caregivers. Such interventions will help caregiver care-receiver dyads, such as Donald and Valerie, to communicate more effectively and salvage their relationship in the midst of dementia's grasp.

Communication Issues for Older Adults

Several physical problems associated with aging create communication difficulties for the majority of older people. In particular, sensation and perception play a primary role in communication capacity and ability. For example, visual acuity decreases with age, making non-verbal cues more difficult to perceive. This alteration has

numerous consequences. First, context cues gradually disappear from conversation. In addition, gestures and subtle facial expressions become extremely hard to recognize. Meanwhile, progressive hearing loss and diminishing sense of touch continue to affect sensation and perception. The former affects an older adult's ability to comprehend spoken language, and the latter hinders an individual's ability to perceive feelings of warmth and social closeness. Other neurological changes lead to increased processing time and reaction time during conversation (Nussbaum, 2000).

The aforementioned changes in sensory ability tend to cause such persons to feel stigmatized by others. When these issues combine, they result in an increased amount of anxiety and decreased confidence for elderly people during conversation (Nussbaum, 2000). As a result, an affected individual may avoid conversation altogether rather than face the anxiety associated with constantly asking communication partners to repeat themselves. Alternatively, individuals may demonstrate compensating behaviors, such as filling in the "blank" for unheard words to maintain conversations, leading to further struggles with comprehension. The combination of these phenomena results in an overall longer duration of conversation and higher frequency of communication breakdown, which may be exceedingly frustrating to participants (Buller, 2005).

Communication and Dementia

The onset of dementia intensifies the previously mentioned communication issues for the elderly. Numerous researchers and clinicians have documented communication disorders related to dementia and noted the escalation of their effects over time. In the early stages of dementia, individuals may demonstrate a lack of certain semantic skills. For example, individuals might have difficulty trying to

generate as many words as possible within a category (Lubinski, 1995). In this primary stage, the ability to comprehend abstract language may also begin to suffer. Although individuals can still easily participate in social conversation, they may struggle to comprehend complex syntax in speech. By the moderate stages of dementia, adults experience difficulty remaining on topic, using pronouns correctly, and retrieving words during conversation. In addition, affected individuals might struggle to understand directions in sequence (Buller, 2005). Eventually the progression leads to the onset of paraphasia, making spoken language extremely hard to interpret. At this advanced stage, individuals can no longer participate in social interactions through communication due to their extreme impairments (Lubinski, 1995). Thus, the countless changes in language ability over time vastly affect the individual's ability to communicate.

Effects of Communication Difficulties

The communication difficulties discussed in the previous section affect several distinct aspects of the lives of IWDs. To illustrate these effects, Banerjee et al (2010) investigated several factors related to quality of life for individuals with dementia. He pinpointed successful communication as one of the most important mechanisms related to good quality of life for these individuals.

Several explanations may account for these results. When unable to express wants and needs through spoken language, individuals with dementia lose the ability to control their care. At the same time, IWDs might begin to lose necessary receptive skills, making it harder for caregivers to explain procedures during care. These dual losses inevitably lead to further confusion for IWDs and may contribute to diminishing feelings of dignity (Nussbaum, 2000). In addition, Banerjee et al (2010) argued power of choice as

necessary for maintaining an adequate quality of life. Without adequate ability to communicate, the IWD cannot exercise control over his life to decide important choices such as what to eat for breakfast or whether or not to sell his home. All in all, studies have concluded that IWDs who have difficulty with communication likely experience a compromised quality of life as a result of these several contributing factors.

Other possible effects of communication loss include aggressive and depressive behaviors, such as those demonstrated by Donald in the introductory vignette. Notably, the Revised Memory and Behavior Checklist, a survey used for caregivers to document observable behavioral patterns associated with dementia, identified several depressive and aggressive behaviors commonly reported by caregivers of IWDs. Aggressive behaviors, such as arguing, verbal aggression, and dangerous threats or actions, and depressive behaviors, such as crying, comments about loneliness, and comments about death, name just a few of the numerous problem behaviors associated with dementia (Teri et al, 1992). These challenging behaviors indicate stress and frustration from the IWD and have a universally negative impact on family caregivers (Robinson, Adkisson, and Weinrich, 2001). Likewise, these reported problem behaviors may contribute to IWD's inability to communicate effectively in other ways.

Similarly, Richter (1995) examined the direct experiences of family members communicating with IWDs. The participants involved in his study reported that loved ones exhibited feelings of anger and agitation, as well as suspicion and wandering behavior. In response, caregivers felt that they needed to communicate with IWDs to reduce the behavior and provide adequate comfort, and in return they experienced angry and agitated communication from their loved ones. Furthermore, some individuals

reported that they felt as though they had lost their loved ones to the disease (Richter, 1995). In essence, the study confirmed that the loss of ability to communicate leads to increased behavior problems among IWDs. Therefore, caregivers must adapt the environment and communication strategies used to prevent as many behavior problems as possible.

The preceding studies provide a background for research to explore the specific effects of communication disorders on IWDs. This study will determine the particular communication challenges that have the biggest impacts on these individuals. In addition, the study will clarify the motives of problem behaviors and their possible relationships to communication discrepancies. The psychological health and communication problems of IWDs will be measured longitudinally to document changes related to the disease's progression.

Caregiver Burden and Well-Being

Despite the independent effects of dementia on IWDs alone, communication difficulties affect both members of an interactional dyad. An extensive amount of research on the concept of caregiver burden describes the extreme psychological effects related to informal caregiving. To clarify, Zarit (1985) describes caregiver burden as “the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative” (p. 23).

Communication struggles between IWDs and caregivers, due to the IWD's changes in personality and failing cognition, as well as limited social support for the dyad may contribute to the intensity these feelings of burden and lead to an eventual burn-out in some caregivers.

To illustrate this relationship, studies have investigated depression and anxiety in caregivers as a result of the significant changes in the personalities of IWDs (Gallagher, 1989). Paspouroufov et al (2007) found that aggressive and threatening behavior demonstrated by the individual with dementia seemed to be positively related to caregiver burden. IWDs may act out with these inappropriate behaviors as a result of anger and resentment. In response, caregivers must manage these difficult behavior problems and work tirelessly to resolve them (Lubinski, 1995). Often, caregivers feel completely isolated when dealing with this burden, leading to further psychological struggle.

Further, since IWDs struggle with communication problems, they cannot provide understanding or comfort to their caregivers, undoubtedly increasing the amount of perceived burden. As an illustration, Savundranayagam et al (2005) investigated the influence of communication difficulties between caregivers and IWDs on caregiver burden. Communication problems were assessed using a sixteen-item inventory, and caregivers identified which issues affected their relationships. The scale included items that targeted both semantic and pragmatic language difficulties. One item, for example, addressed whether the IWD paused often during conversation. Another item considered whether the IWD tended to repeat questions over and over again. Results showed increases in stress for both the caregiver and IWD, indicating that the presence of language problems did increase caregiver burden. In addition to communication, other known stressors that contribute to caregiver burden, such as financial difficulties, continue to mount as the disease progresses with the addition of extra care (Savundranayagam et al, 2005). Altogether, the combination of these stressors over time leads to an incredible amount of caregiver burden.

Unfortunately, high feelings of caregiver burden can lead to an eventual “burnout” in caregivers (Zarit, 1985). According to Alden (2003), caregiver burnout can result in health problems and corresponding behaviors associated with stress. Physical symptoms of burnout include high blood pressure, stomach pain, and headaches. Further, attitudes and behaviors that indicate caregiver burnout include insomnia, short-temperedness, crying spells, and neglect of the care-receiver. For the health and safety of both the caregiver and IWD, at-risk individuals must address stress before it progresses to burnout (Milićević-Kalašić, 2009).

Alternatively, multiple studies have focused on the negative effects of caregiving on mental health and well-being respectively. Most of these studies have reported that caregivers of IWDs have an increased risk for depressive symptoms, anger, and anxiety (Lubinski, 1995). In fact, Zarit et al. (1985) declared caregivers as “hidden victims of Alzheimer’s disease.” Caregivers regularly report anxiety and depression as a result of stress. A variety of sources—including memory and behavior problems—lead to the eventual stress experienced by the individual with dementia. Accordingly, in order to adequately assess the changes in caregiver well-being, researchers must consider these several factors.

Numerous researchers have already taken the step to consider causes of stress and depression in caregivers. For instance, Covinsky et al (2003) conducted a study to examine the causes of depression in caregivers. They found that high dementia severity, low caregiver income, and decreased function in IWDs positively correlated with caregiver depression, suggesting that these issues are risk factors for caregivers. However, Covinsky et al (2003) did not examine communication problems directly.

Rabins and colleagues (1982) conducted a study that measured communication disorders as risks for stress. Although this particular study did not specify the communication disorders prevalent among participants, it suggested that these difficulties prevented the dyad to from exchanging information. They found that seventy-five percent of caregivers who dealt with communication difficulties as a result of dementia considered these issues “caregiving problems” (Rabins et al., 1982). Altogether, these studies reinforce the consideration of communication problems as both stressful and damaging to the caregiver-care receiver relationship.

Other research has considered the direct impact of memory and communication problems on close family members of IWDs. For example, a phenomenon called disconfirmation may occur between younger individuals and IWDs as a result of memory loss. Specifically, individuals with dementia might forget conversations and, eventually, even the faces of their loved ones. This development often devastates family members and makes communication less and less fulfilling for both parties (Nussbaum, 2000). A study by Orange (1991) details family perspectives on communication changes. Incidentally, he found that family members could describe the negative shifts in pragmatic and discourse functioning in IWDs. In addition, relatives spoke about the impact of the communication problems on their relationships specifically. In particular, they discussed feelings of frustration, loneliness and social isolation associated with caring for someone who had significant trouble with communication (Orange, 1991). To conclude, this research indicates that family caregivers are indeed aware of the personality and communication changes in IWDs as well as the emotional impact associated with changes.

Similarly, a related study by Germain et al. (2009) investigated the specific influence of cognitive difficulties on caregiver well-being. Some of the language skills assessed during the study included ability to name object and carry out three step commands. Overall, this study found that cognitive difficulties, particularly surrounding language impairments, intensify caregiver burden. This finding indicates that deficits in language ability likely contribute to strain in the relationship between the caregiver and care receiver. However, results also suggested that caregivers who are more involved in social networks and have ample support from loved ones tend to report decreased feelings of caregiver burden (Germain et al, 2009). Even more, this conclusion suggests that caregivers might “make-up” the loss of social interaction with their loved ones by maintaining other avenues of social support.

The stress associated with caregiving seriously impacts affected individuals. Therefore, future research should determine the factors that lead to this phenomenon. Although, current research has indicated that communication struggles do occur between IWDs and their caregivers, but little has examined the clinical nature of these problems. More research should measure the effects of communication difficulties on caregiver burden and well-being to pinpoint the exact contributions of each type of problem. Above all, future studies should provide detailed explanations of the particular communication difficulties experienced by each IWD to determine the best form of intervention for the caregiver/care-receiver dyad.

Intervention

In response to the various communication problems identified, the literature has reported several intervention strategies to promote successful

communication. These strategies can maintain and, in some cases, improve the quality of communication between caregivers and IWDs, thereby enhancing the social experiences for both parties (Lubinski, 1995). Such techniques make communication management possible for these individuals (Haberstroh, 2011).

Several proposed interventions focus on helping IWDs to improve communication without much consideration for the caregiver. For instance, group therapy with IWDs has been shown to improve receptive and expressive language. Another intervention might include teaching the individual some new adaptive coping strategies to help promote successful communication, such as encouraging the IWD to ask the communication partner to repeat or modify messages for comprehension (Rau, 1993). In addition, cuing strategies may help IWDs with word-retrieval problems in particular. This form of therapy encourages IWDs to use a semantically related phrase in place of the intended word in hope of eventual retrieval. Moreover, therapists might encourage using sequencing techniques or life experiences when explaining stories and abstract ideas to avoid communication breakdowns (Lubinski, 1995). Memory books as a form of augmentative and alternative communication have increased the number of informative utterances demonstrated by IWDs in nursing homes (Bourgeois et al, 2001). Furthermore, these strategies can indeed lend to improvement in expressive and receptive language abilities for IWD.

Other therapies focus on the caregiver rather than the IWD alone. For example, the caregiver should increase opportunities for conversation and allow IWDs more control during interactions. Caregivers can also learn to enhance verbal interactions with IWDs by modifying syntactic and lexical components of their speech (Small et al., 2003;

Rau, 1993). To illustrate, Small et al (2003) discovered that when caregivers simplified sentences, fewer breakdowns in communication occurred between the dyad. Interventions that incorporate forms of intervention for both the caregiver and care-receiver rather than just the caregivers alone, such as through the use of memory aids and caregiver training, yield successful results in increasing and enhancing communicative interactions (Egan et al, 2010).

Caregivers can implement communication strategies even in the face of a behavioral outburst. Aggarwal et al (2003) found that as a result of being unable to communicate, IWDs became more depressed or aggressive. However, through the implementation of communication strategies, such as asking more broad and open-ended questions to elicit more information during conversation, and implementing person-centered care, interactions between caregivers and care receivers will improve to enhance social competence and independence for the individuals with dementia (Aggarwal et al, 2003).

As has been noted, several of the current interventions to improve communication focus on either the IWD or caregiver alone to improve communicative behaviors. Most strategies for caregivers focus on expressive rather than receptive communication (Rau, 1993). That is, clinicians should give more clear instruction as to how to improve the caregiver's speaking skills to accommodate individuals with dementia, but seldom teach strategies for understanding the communication of IWDs. Further research will clarify the need for strategies targeting both members of the communication dyad. Interventions focused around this dyadic relationship could improve outcomes for the caregiver and care-receiver

Summary and Implications

Current research has documented several changes in communication as a result of aging. Consequently, when individuals who already face these changes begin to experience the effects of dementia, communication becomes even more difficult.

Unfortunately, each progressive stage of the syndrome marks the development of additional communication problems for affected individuals (Lubinski, 1995). The inability to communicate effectively has debilitating effects on individuals with dementia, as they lose the ability to control decision making and care routines (Banerjee et al, 2010). Just as the individuals themselves are negatively affected, dementia impacts the lives of caregivers, too. In some cases, caregivers report feelings of burden (Zarit, 1985) and burnout (Alden, 2003). Communication difficulties between caregivers and IWDs may relate to these consequences (Savundranayagam, 2005). Interventions to increase communication between IWDs and caregivers have been effective for more frequent, quality interactions with caregivers (Rau, 1993).

Despite the extensive research available on communication disorders and dementia, very little has examined the exact psychological effects on the IWD and caregiver as a result of such challenges. Likewise, very little literature details the impact of communication disorders associated with dementia on caregiver burden and well-being. Another issue with the current research on dementia and communication problems concerns the methods that studies employ. More researchers should consider the methods of Aggarwal et al (2003) and adopt longitudinal measures to examine the changes in communication of IWDs throughout the progression of the disease. Because each stage involves different types of language and communication problems, researchers should

consider different intervention strategies depending on each particular stage. Future studies should also consider larger sample sizes of caregivers and IWDs to encompass a wider range of cultural and socioeconomic backgrounds. The study conducted by Savundranayagam et al (2005) found compelling evidence regarding the effects of communication problems on caregiver burden. However, the study only included eighty-nine participants—not generalizable to the entire population of caregivers. Therefore, past studies have indicated several implications for alternative methods of future studies.

Further research will pave the way for new interventions to increase communication between caregivers and care-receivers. With the help of this necessary research, clinicians will employ more dyad-focused interventions and, thereby, lessen caregiver stress. Successful intervention strategies will lead to increased quality of life for both the IWD and the caregiver, yielding more positive outcomes for all who cope with this devastating syndrome.

Chapter 2

Current Study

Purpose

To determine whether certain types of communication are related to specific caregiver outcomes

Hypotheses

1. Positive communication exhibited by the IWD will have a positive association with a caregiver's positive affect and a negative association with caregiver anger, depression, and role overload.
2. Depressive communication exhibited by the IWD will have a negative association with a caregiver's positive affect and a positive association with caregiver anger, depression, and role overload.
3. Aggressive communication exhibited by the IWD will have a negative association with a caregiver's positive affect and a positive association with caregiver anger, depression, and role overload.
4. Increases in a caregiver's anger, depression, and role overload over time will be associated with increasing aggressive and depressive communication and decreasing positive communication. Decreases in a caregiver's anger, depression and role overload over time will be associated with decreasing aggressive and

depressive communication and increasing positive communication exhibited by the IWD.

5. Increases in a caregiver's positive affect over time will be associated with increasing positive communication and decreasing aggressive and depressive communication exhibited by the IWD. Decreases in a caregiver's positive affect over time will be associated with decreasing positive communication and increasing aggressive and depressive communication exhibited by the IWD.

Chapter 3

Design and Methods

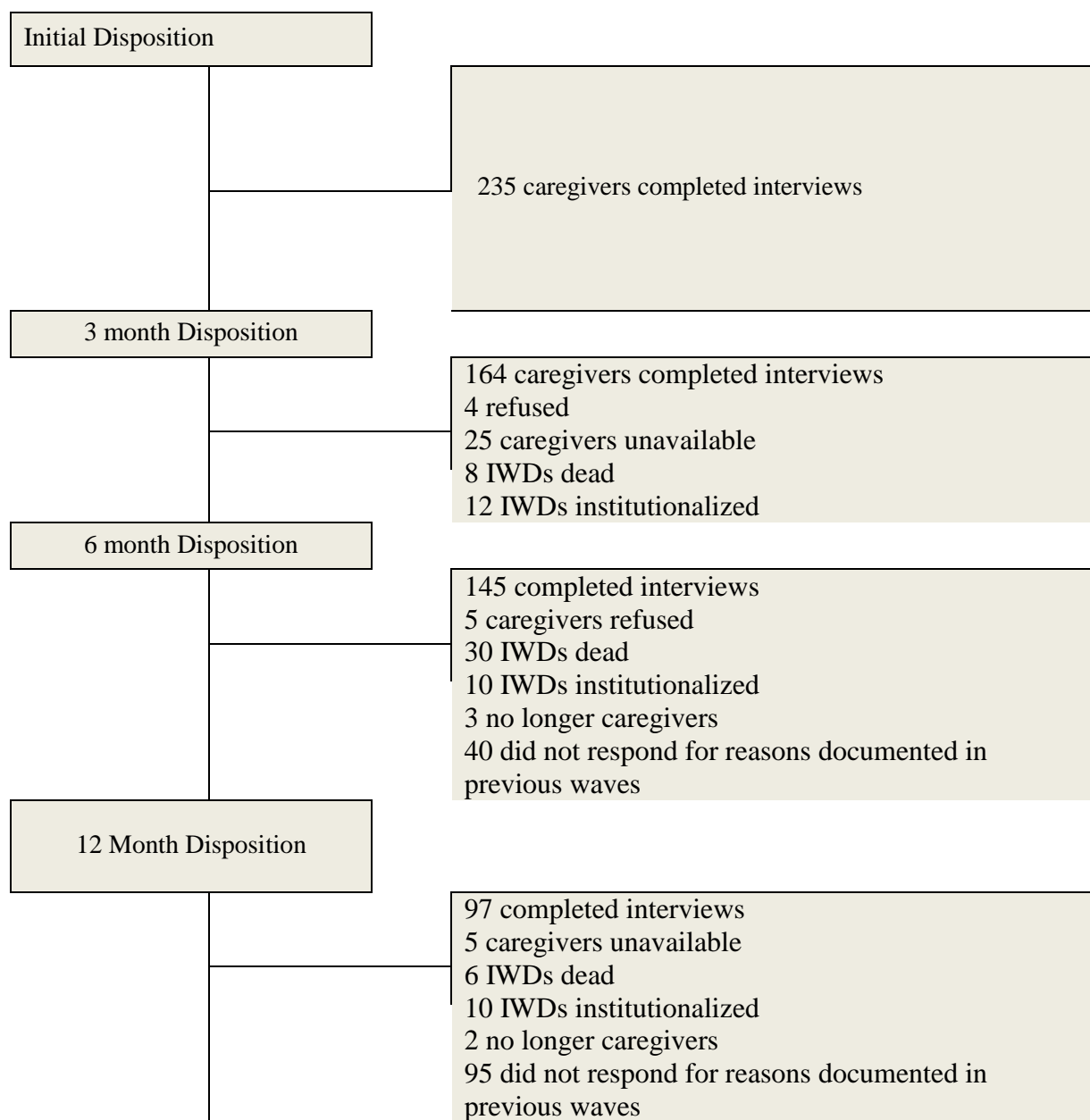
Participants

The present study is part of the Family Caregiving and Respite Evaluation Study (Family CARES). The Family CARES study investigated the effects of adult day services (ADS) on caregiver stress. The sample consisted of 235 dyads of IWDs and their family caregivers. Participants included individuals enrolling a relative in ADS recruited by staff from various ADS programs. In addition, the research team recruited a control group comprised of participants who did not take advantage of ADS. Researchers recruited these individuals through various community resources, such as the Alzheimer's Association and local in-home respite programs. In order to qualify for participation in the study, individuals had to have a valid dementia diagnosis and live in the same household as the informal (family) caregiver. The majority of participants resided in New Jersey, although the study also included one county from Pennsylvania.

The current study utilized baseline data (collected before ADS began), second wave data (collected three months after beginning ADS), third wave data (collected six months after beginning ADS), and fifth wave data (collected one year after beginning ADS). The fourth wave data (collected 9 months after beginning ADS) was used to gather information about health utilization and did not include the communication or behavior items. Thus, the fourth wave of data was not analyzed as part of the study.

All 235 caregivers completed the initial interview, 164(70%) completed the three month interview, 145(62%) completed the 6 month interview, and 97(41%) completed the twelve month interview. Caregivers dropped out of the interview process for various reasons over the twelve month period. Over the year, thirty-two(14%) IWD's were institutionalized and forty-four(19%) died, accounting for some of the missing data. Figure 1 describes the rest of the missing cases.

Figure 1. Explanation of Attrition



Notes: IWD = individual with dementia;

Table 1 presents demographic information. The average age of the caregivers in the study was 62.79 years. There were more female caregivers (79.5%) than male

caregivers involved in this study. In addition, forty-six percent of the sample included spouses of IWDs, while the latter fifty-four percent consisted of sons, daughters, son/daughter in-laws, and others.

Table 1 Demographic Information

	<i>M</i>	<i>SD</i>	Range
Treatment Group (ADS=1)	1.37	0.49	0-1
CG's characteristics			
Age	62.79	12.74	37-87
Education Level	13.51	2.24	0-17
Income	4.79	2.91	1-11
Duration of care (months)	33.47	31.50	1-192
Female (yes=1, no=0)	0.79	0.41	0-1
Spouse (yes=1, other=2)	1.54	0.50	1-2
White (yes=1, no=2)	1.14	0.34	1-2
Married (yes=1, no=2)	1.26	0.44	1-2
Employed (yes=1, no=0)	0.32	0.47	0-1
IWD's characteristics			
Age	80.08	8.12	51-101
Female (yes=1, no=0)	0.57	0.50	0-1
ADL impairment(0-39)	24.36	8.31	0-39

Note: CG=Caregiver, ADL=Activities of Daily Living, IWD=Individual with Dementia
 Caregiver education ranged from no school (0) to post-graduate level (17)
 Caregiver Income ranged from less than \$10,000 (1) to \$100,000 and over (11)

Procedures

All procedures in the Family CARES study were previously approved by the Penn State University Institutional Review Board (IRB). Trained research assistants interviewed caregivers in their households. During these 90-minute, face-to-face interviews, caregivers disclosed information about themselves and the IWD. Researchers only assessed IWDs to determine cognitive status through the Mini-Mental State Exam (MMSE) (Folstein, Folstein & McHugh, 1975). Caregivers provided information for all other measures of the study.

Using the Weekly Record of Behavior (WRB), caregivers reported frequency of behaviors demonstrated by the IWDs as well as the resulting stress (Son et al, 2007). Prior work with the WRB suggests that the measure has both high stability and reliability (Fauth et al, 2006). The WRB assessed the frequency of fifty-three behaviors demonstrated by IWDs. Caregivers were asked whether the behavior had occurred in the past week, how often it occurred, and how stressful it was. The present study focused primarily on behaviors surrounding aggressive, depressive, and positive communication. A set of twenty-nine items from the WRB addressed communication between the caregiver and care receiver. A factor analysis with varimax rotation using principal components extraction yielded three factors from these twenty-nine items. Sixteen items did not load on any factor and were dropped from the analysis. The three factors consisted of aggressive, depressive, and positive communication items respectively. All three factors produced Eigenvalues over 1.4. The aggressive communication items had factor loadings ranging from 0.44 to 0.77, positive communication items had loadings from 0.69 to 0.82, and depressive communication items had loadings from 0.55 to 0.74. Table 2 presents the exact values produced by the factor analysis.

Table 2 Factor Analysis: Rotated Component Matrix

	Depressive	Positive	Aggressive
# of times relative expressed feeling sad or hopeless	0.72	0.14	0.06
# of times relative cried and was tearful	0.55	-0.01	0.26
# of times relative commented on death of self or	0.74	-0.02	0.05
# of times relative talked about feeling lonely	0.64	0.12	0.10
# of times relative mentioned worthlessness, failure,	0.69	0.05	-0.13
# of times relative took part - showed interest in	0.03	0.69	-0.03
# of times relative took part - showed interest in	0.02	0.79	0.16
# of times relative talked about something with	0.06	0.82	0.02
# of times relative showed enjoyment or appreciation	0.08	0.70	-0.13
# of times relative argued, complained, or was	0.51	-0.11	0.52
# of times relative was verbally aggressive	0.12	0.03	0.72
# of times relative displayed jealousy	0.39	-0.05	0.44
# of times relative threatened to hurt others	-0.10	0.05	0.77

Notes: Extraction Method: Principal Component Analysis.

Communication Scales

Using the factors yielded during analysis, I constructed scales to determine three different styles of verbal communication: positive, depressive, and aggressive. Although the WRB did not specifically target communication disorders, I chose to look at aggressive and depressive communication items, as these behaviors may indicate a lack of ability to communicate effectively. In addition, I elected to examine behaviors indicating more positive communication to represent successful communication elicited by IWDs. The positive communication measure contained four items. Specifically, positive communication occurred when the IWD voluntarily participated in activities, took part or showed interested in conversations, talked about something with the caregiver, or showed enjoyment or appreciation. The aggressive communication measure

included four items as well. To illustrate, aggressive communication occurred when the IWD argued or complained, was verbally aggressive, displayed jealousy, or threatened to hurt others. Finally, the depressive communication scale contained five items. Examples of items included times when the IWD expressed feelings of sadness and hopelessness, cried or was tearful, commented about death of self or others, talked about feeling lonely, or mentioned worthlessness, failure or being a burden. For all three of the communication measures, caregivers reported whether or not each behavior occurred and the number of times each behavior occurred in the past week. For the depressive and aggressive communication items, caregivers also reported how stressful the behavior was on a scale ranging from 1 (indicating “not at all”) to 5 (indicating “very stressful”).

I constructed the three previously mentioned scales by summing the number of times each particular communication behavior occurred, respectively. To measure the stress associated with the aggressive and depressive communication dimensions, I created additional weighted scales. To construct these stress appraisal scores, I multiplied the number of times each behavior occurred by the corresponding stress level and summed the results.

Outcomes

Caregiver outcomes included measures of depression, anger, positive affect, and role overload. I selected these particular measures to document the negative as well as the positive consequences associated with the various forms of communication experienced by caregivers. In other words, I reasoned that depression and overload might be related to depressive communication, anger to aggressive communication, and positive affect to positive communication.

To assess the frequency of caregiver depression, I used the CES-D depression scale (Radloff, 1977). This standard scale measures twenty different items to document the number and intensity of depressive symptoms that have occurred over the past week. One example of an item from this scale addressed whether caregivers felt lonely. To respond, caregivers indicated the frequency of each symptom by choosing a response ranging from “rarely or never” (0) to “most of the time” (3). I combined the twenty items to form a summary score, with higher scores indicating increased depressive symptoms.

Similarly, overload, which refers to the feelings of exhaustion and burnout experienced by caregivers, was assessed using a 6-item scale (Pearlin et al., 1990; Zarit et al, 1998). Using the provided instructions, caregivers reported how often they experienced various feelings associated with overload (Kim et al, 2012). Some examples of questions from this scale include, “How often do you have time for yourself,” and “How often do you feel you are able to relax?” Participants answered from a response sheet listing choices from “none of the time”(0) to “all of the time” (3). A summary score was calculated from these responses with a higher score designating more feelings of overload.

I measured caregiver anger using a scale consisting of four items. Specifically, these items assessed how often a caregiver felt critical of others or became angry easily. Participants indicated responses to these questions ranging from, “not at all” (0) to “very much” (3) (Derogatis et al, 1973; Pearlin, et al, 1990). Once again, I combined these responses to form a summary score; low score results indicated a lower amount of anger, while higher scores demonstrated increased caregiver anger.

Finally, the positive affect scale was constructed from a 10-item scale that assessed the frequency of caregivers' positive emotions throughout the day (PANAS; Watson et al., 1988). One question from the positive affect scale asked how often caregivers felt enthusiastic. In response, participants chose answers ranging from, "not at all" (0) to "extremely" (4). In a similar manner to the previous scales, I combined the responses to form a summary scale where a higher score indicated more positive affect, and a lower score indicated less positive affect.

Covariates

To control for other possible factors related to the outcome measures, I included demographic information as predictors. These specified control variables included the caregiver's education level and the kin relationship between the caregiver and IWD, and the IWD's ability to perform activities of daily living (ADLs). Caregiver education level was measured by how many years of education the caregiver had received. Using these answer choices, participants indicated whether they had completed elementary school, high school, college, or graduate school. In addition, I thought that communication problems might be more difficult for spouses of IWDs, so I wanted to incorporate a variable to compare spouses to other caregivers. I evaluated the kin relationship variable by asking caregivers whether they were spouses of the IWD. If the caregiver was not a spouse of the IWD, I identified him/her as "other." Finally, I measured the IWD's ability to perform ADLs using a scale of thirteen items. These specific items measured whether or not the individual was able to perform daily tasks such as housework, shopping, and answering the telephone (IADL; Lawton, 1971) and personal activities such as eating, dressing, and bathing (PADL; Katz, et al., 1963).

Study 1: Cross-Sectional Analysis

For the first study, data was analyzed using version 20 of the SPSS statistical software. I performed multiple linear regressions to assess the main hypotheses and determine the outcomes related to each form of communication. In four regression models, caregiver depression, positive emotions, caregiver anger, and caregiver overload were the outcome variables, respectively. For each of the four models, independent variables were entered simultaneously: control variables (kin relationship between caregiver and IWD, caregiver education, and ability to perform activities of daily living), aggressive communication, positive communication, and depressive communication. This model served to determine the amount of depression, anger, overload and positive emotions associated with each form of communication.

Study 2: Longitudinal Analysis

For the second study, I performed growth curve modeling (also known as multilevel or random coefficient modeling) using longitudinal data with four waves from the Family Cares Study. The data was analyzed using version 9.3 of SAS statistical software, and I used SAS PROC MIXED procedure (Littell, et al 1996) to examine the main effects of the predictors on caregiver depression, overload, positive affect, and anger over time. Such multilevel models include both a level-1 model to describe intra-individual change, as well as a second level model that demonstrates between-person differences in longitudinal change (Singer & Willett, 2003). Each of the multi-level models was based on measurements collected at the baseline, second, third, and fifth waves of the study.

Three of the models tested the negative caregiver outcomes (caregiver depression, anger, and overload) and one tested positive affect. For all four of the models, I examined the main effects of time (baseline through wave five), and communication dimensions (aggressive, depressive, and positive), controlling for other covariates that are known to affect caregivers' longitudinal affective well-being (IWD's ability to perform ADLs, caregiver education, and kin relationship).

I performed the growth curve analysis in two blocks. For the first block, I was primarily interested in discovering whether or not there was a longitudinal effect for each outcome. For each of the four models, I tested linear, quadratic, and cubic effects of time. Concerning Models one and two (Depression and Anger), I did not find a significant time effect, prompting the removal of this predictor. For these two models, I proceeded with a second set of analyses to examine the within-person and between-person affective trajectories and covariation for both outcomes without the time predictor.

In contrast, the linear time effect did show significance for models three and four (Overload and Positive Affect). Thus, for these two models, I performed the second set of analyses including the time effect to further analyze the within-person and between-person trajectories of the outcomes.

The growth curve model (levels 1 and 2) appears below. Each caregiver (i)'s, individual outcome (depression, anger, positive affect, overload) at time t , y_{it} , is a function of β_{i0} (the within-person intercept at baseline), β_{i1} (the within-person slope of depressive communication), β_{i2} (the within-person slope of aggressive communication),

β_{i3} (within-person slope of positive communication), β_{i4} (the individual-specific IWD ADL ability level), and e_{it} (the individual-specific residual error). Since the time effect was significant in the caregiver overload and positive affect models, a fifth parameter to represent linear time, β_{i5} , was added to the function. The β s were then defined in the Level 2, between-person, equations. β_{i0} was specified as a function of an intercept (γ_{00} , the grand mean of affect), caregiver education level (γ_{10} , when kin relationship is non-spouse), and whether caregiver is spouse (γ_{20} , when caregiver has no formal education) as well the between-person random effect (μ_{i0} , between-person differences in within-person intercept).

Level 1 Equation (Within-Person):

$$y_{it} = \beta_{i0} + \beta_{i1}(\text{depressive communication}_{it}) + \beta_{i2}(\text{aggressive communication}_{it}) + \beta_{i3}(\text{positive communication}_{it}) + \beta_{i4}(\text{ADL Total}_{it}) + [\beta_{i5}(\text{Time}_{it} \text{ (only included for positive affect and caregiver overload, Models 3)})] + \epsilon_{it}$$

Level 2 Equations (Between-Person):

$$\beta_{i0} = \gamma_{00} + \gamma_{10}(\text{caregiver education}_i) + \gamma_{20}(\text{spouse}_i) + \mu_{i0}$$

$$\beta_{i1} = \gamma_{01}$$

$$\beta_{i2} = \gamma_{02}$$

$$\beta_{i3} = \gamma_{03}$$

$$\beta_{i4} = \gamma_{04}$$

$[\beta_{i5} = \gamma_{05}$ (only included for positive affect and caregiver overload outcomes in Models 3 and 4)]

Chapter 4

Results

Study 1: Cross-Sectional Analysis

I performed linear regressions to examine associations between the four measures of caregiver outcomes (depression, anger, overload, and positive affect) and the three communication patterns. In addition, I controlled for the caregiver's level of education, relationship to IWD (spouse or non-spouse), and the IWD's ability to perform activities of daily living as control variables. All four of the models produced significant "F" values, indicating that the regression models fit the data well. I will examine each dependent measure and its associations as determined by the regression analyses.

Caregiver depression as an outcome showed a significant, positive relationship with aggressive ($\beta = 0.157, p < 0.05$) and depressive ($\beta = 0.172, p < 0.05$) communication as predictors. Positive communication ($\beta = -0.195, p < 0.01$) had a significant negative association with caregiver depression. However, none of the covariates had significant associations with caregiver depression.

Anger had a significant, positive relationship with depressive communication ($\beta = 0.271, p < 0.001$) and a significant, negative association with positive communication ($\beta = -0.311, p < 0.001$). Two of the covariates also had significant associations with caregiver anger. The IWD's ability to perform ADLs had a negative relationship with caregiver anger; the more dependent the IWD was on the caregiver, the lower the caregiver's anger

score. Kin relationship had a positive relationship with caregiver anger, indicating that caregivers who were not spouses tended to report more anger.

The third outcome variable, caregiver overload, had a significant positive association with aggressive communication ($\beta = 0.186, p < 0.05$) and a significant negative association with positive communication ($\beta = -0.050, p < 0.01$). In addition, kin relationship demonstrated a significant positive relationship with this measure ($\beta = 0.146, p < 0.05$); caregivers who were not spouses reported higher feelings of overload.

For positive affect, none of the communication patterns showed significant associations. However, the IWD's ability to perform ADLs did show a significant, negative association with positive affect ($\beta = -0.176, p < 0.05$). That is, the less dependent an IWD was on a caregiver, the more positive affect reported by the caregiver.

In closing, I found that depressive communication had a significant positive association with caregiver anger and depression, aggressive communication had a significant positive association with caregiver depression and overload, and positive communication showed a significant negative association with caregiver depression and anger.

Table 3 Multiple Linear Regressions

	Depression	Anger	Overload	Positive Affect
	β (s.e)	β (s.e)	β (s.e)	β (s.e)
Aggressive Communication	0.145* (4.999)	0.007 (0.019)	0.059* (0.024)	-0.046 (0.052)
Depressive Communication	0.114* (0.051)	0.050*** (0.014)	0.034 (0.017)	-0.008 (0.037)
Positive Communication	-0.423** (0.152)	-0.186*** (0.041)	-0.050** (0.052)	0.203 (0.111)
Caregiver Education	-0.108 (0.312)	0.028 (0.084)	-0.144 (0.108)	-0.264 (0.229)
IWD ADL total	0.119 (0.084)	-0.051* (0.023)	0.054 (0.029)	-0.156* (0.063)
Spouse vs. Other	-0.489 (1.387)	0.848* (0.373)	1.044* (0.478)	0.927 (1.020)
Model R-square	0.140	0.181	0.146	0.070
F	5.570***	7.535***	5.873***	2.565*

Note: IWD= Individual with Dementia, ADL=Activities of Daily Living, Dyad N=235

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Study 2: Longitudinal Analysis

After determining these cross-sectional results, I opted to investigate the association of changes in communication styles and change over time in the four outcome variables: depression, anger, overload, and positive affect. I considered four waves of interviews: baseline, 3 months, 6 months and 12 months.

I used an auto regression (AR1) error structure (shown in Table 4) for every model in the MLM analysis to control for changes from one wave to the next. This structure ensured that the models fit the data well.

The first column presented in Table 4 shows caregiver depression as the outcome variable. Using MLM in a preliminary analysis, I modeled the possible time trends (linear, quadratic, and cubic) in changes of depression. In this model, I did not find any general time trend for between-person longitudinal change in levels of depression. Significant random intercepts showed that caregivers differed individually in their overall

levels of depression over time ($\sigma^2=45.905$, $p<.001$). However, the between-person level of depression barely changed over the four waves. That is, there was not a significant increasing or decreasing trend over time for caregiver depression.

In the second set of analyses, I entered communication patterns over time to explain within-person associations in depression over time. In this analysis, I also controlled for caregivers' education, kin relationship types, and IWDs' functional dependency. The aggressive communication variable yielded a significant positive relationship ($\beta= .156$, $p< 0.01$), and positive communication showed a significant negative relationship ($\beta= - .199$, $p<0.05$) as predictors of caregiver depression over time. In other words, higher aggressive communication and lower positive communication were both associated with higher caregiver depression. Among the covariates, the IWD's ability to perform ADLs also demonstrated a significant positive association with within-person depression. Specifically, as the ADL Impairment score increased over time, caregiver depression also increased. None of the other control variables were significantly associated with caregiver depression.

The second column presented in Table 4 investigated caregiver anger over time as the dependent variable. My preliminary analysis did not reveal a between-person longitudinal trend using time as the within-person predictor. Nonetheless, the significant random intercept showed that caregivers had significant between-person differences in their overall level of anger ($\sigma^2=3.773$, $p<.001$). In the second set of analyses, using communication variables as predictors, I found significant covariations between all three of the communication predictors and caregiver anger. That is, aggressive and depressive communication as predictors showed significant positive associations ($\beta= .039$, $p< .001$;

$\beta = .03, p < .01$) and positive communication showed a significant negative association ($\beta = -.08, p < .01$) with caregiver anger. Thus, higher aggressive and depressive communications were associated with more caregiver anger, whereas higher positive communication was associated with lower caregiver anger over time. None of the covariates (kin relationship, IWD's ADLs dependency, or caregiver education) showed significant associations with caregiver anger.

Next, I analyzed caregiver overload as a dependent variable (shown in Table 4). Unlike the depression and anger analyses, this analysis revealed a linear time trend of longitudinal change in overload. Time, as a within-person predictor, demonstrated a significant negative relationship between caregiver overload, showing decreasing level of role overload over time ($\beta = -.19, p = .013$).

When I performed the second set of analyses (shown under "Overload, Model 2" in Table 4) by adding communication patterns into the model along with the linear time predictor, linear time remained a significant predictor ($\beta = -.16, p = .03$). The random intercept indicated significant between-person variations in overall levels of caregiver overload ($\sigma^2 = 5.558, p < .001$). Additionally, depressive and aggressive communication both displayed significant positive relationships as predictors of changes in overload over time ($\beta = .03, p = 0.004$; $\beta = .05, p = 0.0002$). These effects suggested that decreasing depressive and aggressive communication were associated with decreasing overload over time. In addition, positive communication as a predictor of caregiver overload showed a significant negative relationship, suggesting that as caregiver overload decreased, positive communication increased. None of the other covariates (kin relationship, IWD's ADLs dependency, or caregiver education) were significant.

Positive affect (shown in table 4) as an outcome variable showed a borderline significant linear time trend for longitudinal change in the preliminary analysis ($\beta=-.32$, $p=.08$). When the communication pattern variables were added to the model as additional within-person predictors, the linear time effect was no longer significant. The random intercept showed significant between-person variability in caregivers' general level of positive affect over time ($\sigma^2=26.567$, $p<.001$). Positive communication showed a significant positive association with positive affect ($\beta=.17$, $p=.03$). That is, lower positive communication was associated with lower positive affect over time. As for the other covariates, the IWD's ability to perform ADLs showed a significant negative effect. Thus, the IWD's decreased ability to perform ADLs was related to increased positive affect. The rest of covariates were not significant.

Table 4 Multilevel Modeling (MLM) Results

	Depression	Anger	Role Overload		Positive Affect	
	β (s.e.)	β (s.e.)	β (s.e.)		β (s.e.)	
<i>Fixed effects</i>						
Intercept	14.560*** (4.310)	3.393** (1.110)	Model 1 11.750*** (0.217)	Model 2 10.103*** (1.3810)	Model 1 22.306*** (0.486)	Model 2 26.338*** (3.177)
Linear time			-0.187* (0.075)	-0.157* (0.074)	-0.319 † (0.185)	-0.254 (0.183)
Aggressive Communication	0.156*** (0.041)	0.039*** (0.012)		0.051*** (0.013)		-0.016 (0.033)
Depressive Communication	0.059 (0.034)	0.030** (0.010)		0.032** (0.011)		-0.009 (0.028)
Positive Communication	-0.199* (0.100)	-0.083** (0.028)		-0.063 (0.032)		0.169* (0.078)
IWDs' ADLs function	0.189** (0.062)	-0.001 (0.017)		0.037† (0.021)		-0.157** (0.049)
Caregiver's Education	-0.297 (0.274)	-0.041 (0.070)		-0.059 (0.088)		-0.213 (0.2)
Spouse vs. Other	-0.295 (1.216)	0.641* (0.310)		0.852* (0.389)		0.947 (0.885)
<i>Random effects</i>						
Intercept VAR (σ^2)	45.905*** (11.825)	3.773*** (0.562)	5.879*** (0.919)	5.558*** (0.751)	22.013*** (5.306)	26.567*** (3.901)
Residual VAR	64.3715*** (10.214)	4.219*** (0.350)	5.636*** (0.625)	4.716*** (0.346)	36.734*** (4.575)	30.620*** (2.216)
AR(1)	0.398*** (0.100)	0.002 (0.081)	0.215* (0.096)		0.295** (0.092)	
-2LL	4520.200	2964.600	3070.700	2856.800	4184.500	3940.300
AIC	4526.200	2970.600	3076.700	2860.800	4190.500	3944.300

Note: Dyad $N=106-214$, ADL= Activities of Daily Living

† $p < 0.1$; * $p < 0.05$; ** $p < .01$; *** $p < .001$

Chapter 5

Discussion

Cross-Sectional Study

I aimed to explore the various patterns of communication expressed by IWDs and their effects on caregiver well-being. The cross-sectional analysis revealed that communication patterns indicating negative affect (aggressive and depressive communication) displayed by IWDs resulted in similarly negative outcomes (caregiver depression, anger, and overload) for the caregiver. Taken separately, I found that depressive communication patterns from IWDs predicted higher depression and anger in caregivers. Likewise, more aggressive communication was related to more caregiver depression and feelings of overload. On the other hand, positive communication patterns from IWDs were associated with less caregiver anger and depression. Altogether, the analyses indicated that aggressive and depressive communication items lent to more feelings of caregiver burden, and positive communication was associated with less of these feelings, confirming the original hypotheses.

To my surprise, this cross-sectional analysis did not show a significant relationship between positive communication and positive affect. This lack of significance could be related to the relatively small sample size (only 214 dyads) as well as the complex relationship between aspects of the caregiving relationship and positive outcomes. Current research suggests that positive affect is associated with several factors, including presence of an adequate support system (Farran, 1997). Perhaps for the

caregivers in the current study, positive affect is more strongly associated with factors such as support than with communication patterns.

As a follow-up cross-sectional study, researchers could investigate the correlation between these dimensions of communication and positive affect, depression, and anger outcomes among IWDs. If results similar to the current study could be replicated in the follow-up, there would be sufficient evidence to conclude that the aggressive and depressive forms of communication are related to negative outcomes for both caregivers and receivers. This conclusion would further support the need for interventions to improve outcomes for both caregivers as well as IWDs.

Longitudinal Study

All four of the longitudinal models showed significant between-person variability in caregivers' overall affective well-being, as estimated by the intercept variances. There were no significant between-person time trends for depression and anger. Although the slopes for these models were not significant, the findings indicate that the between-person differences are associated with the differing communication patterns among the dyads. In both of these two models, I found within-person associations between the communication patterns and caregivers affective well-being.

In contrast, role overload and positive affect as outcomes both showed negative time trends. Specifically, role overload decreased over time and demonstrated significant within-person associations between communication patterns and caregiver affect. For positive affect as an outcome, the within-person association with time disappeared after the communication patterns were added as predictors. Nonetheless, positive affect had a significant association with positive communication as predictor.

Results indicated that two of the four outcome variables (caregiver depression and anger) did not have a significant relationship with time as a predictor. Several reasons could account for the lack of significance in these patterns of affective change over time. For example, between waves one and four, about half of the original sample dropped from the study. It is possible that the most angry and depressed caregivers were more likely to be ineligible for the study after placing their relatives in nursing facilities. Another important consideration concerns the relatively short period of time (12 months) covered by waves one through four. If these variables were measured over a longer period of time, more clear trends might emerge.

In addition, past research has noted that multiple factors are correlated with both caregiver anger and depression measures. For example, background characteristics (age, race, financial income, hours spent caregiving) of both caregivers and IWDs are associated with caregiver depression (Covinsky et al, 2003). Similarly, caregiver anger has been connected to critical and hostile attitudes (Dunkin et al, 1998), among other sources of stress. These complex relationships between possible confounds and my outcome variables could contribute to the lack of a significant time trend. Nonetheless, the results from the MLM did confirm the cross-sectional study's findings about the associations between the various patterns of communication and caregiver outcomes.

Role overload as a caregiver outcome revealed a negative time trend along with aggressive and depressive communication patterns. The items contained in the aggressive and depressive communication measures (crying, verbal threats, and comments about death) would logically contribute to the stress associated with caregiver overload and burnout, and so I expected this outcome to increase over time. However,

over the period of four waves, this measure showed a steady decline. Past research has noted that overload correlates with a caregiver's sense of mastery (Aneshensel et al, 1993). Thus, if caregivers felt more able to tackle the demands of their roles over time, a decline in feelings of overload would seem reasonable. Although the opposite would normally be expected, the results indicate that overload is positively associated with the IWD's ability to perform ADLs. According to previous literature, over time, caregivers may expect decreased ability of the IWD to perform ADLs, allowing them to anticipate more dependency from the IWD. As a result, the caregiver may gradually adapt to handling these changes in dependency, decreasing feelings of overload (Aneshensel et al., 1993).

Finally, I confirmed a significant negative time trend for positive affect, but this trend disappeared when other predictors were considered. The decrease in positive affect over time as a result of caregiving seems logical, considering the declining health of the IWD and addition of caregiving responsibilities. Still, as previously mentioned, the complex relationship between various predictors and positive affect could lead to effects from confounding variables (Farran, 1997). These effects could explain the lack of a significant time trend with the communication patterns.

As a future direction, a structural equation model could be constructed to further examine the causal relationships between communication and caregiver overload, depression, anger, and positive affect. Such a model would be able to more directly determine the causal effect of communication predictors on the affective outcomes.

Overall Interpretation

Why do IWDs exhibit these aggressive and depressive communication behaviors in the first place? Drawing from previous literature, these individuals likely experience difficulty achieving simple wants and needs, as well as more complex communication goals (social closeness and information transfer) (Light, 1988; Blackstone, 1996). Therefore, it is plausible that the depressive and aggressive behaviors are related to the IWD's decreased ability to communicate. According to Smith and Buckwater (2005), behavioral symptoms such as those analyzed in the current study are almost always attempts to communicate in spite of impaired language ability.

In this study, I found that positive communication was associated with decreased feelings of caregiver burden. Therefore, to decrease overall caregiver burden, it is necessary to decrease aggressive and depressive communication and increase positive communication as much as possible. In order to increase such positive communication, IWDs must have the ability to successfully communicate without resorting to such depressive and aggressive communication behaviors. Thus, it is necessary to employ communication strategies for both caregivers and receivers.

The positive communication exhibited by IWDs could relate to a caregiver's willingness to encourage verbal communication from the IWD, in spite of deficits related to the relative's dementia. Interventions constructed to increase such positive communication, should, according to my findings, decrease aggressive and depressive communication, as well as overall caregiver burden. The results of this study reinforce the importance of successful communication between the IWD and caregiver, not just for the sake of the IWD himself, but also for the caregiver's well-being. Future research must focus on developing and employing interventions for IWDs to communicate more

successfully, so that they will not resort to these aggressive and depressive compensating behaviors.

These findings support previous research regarding the behaviors of IWDs and their effects on caregiver burden (Pasporourov, 2011; Gallagher et al, 1989). Bourgeois et al (2010) describe a number of AAC tools developed to assist IWDs to communicate successfully with caregivers. For example, low-tech communication tools, including boards and memory books, can alleviate memory and word-finding problems. Bourgeois suggests that AAC therapy for IWDs may also require training for caregivers to learn how to guide interactions. In addition, Orange (1998) notes the importance of teaching caregivers proper strategies to encourage conversation with IWD.

Still, as described by Young et al (2011), information for caregivers and professionals who work with IWDs regarding communication strategies is not always readily available. According to Young's study, professionals and caregivers reported that the communication advice available was extremely general and lacked credibility (Young et al, 2011). Such techniques encouraging positive communication could be incorporated into informal interventions (such as in the form of presentations at Alzheimer's Association meetings) and should be readily available for both caregivers and IWDs. However, the previously mentioned studies do not specifically suggest the possibility of combining IWD and caregiver conversational strategies as a way to improve communication between the dyad. That is, many of the studies focus on either the IWD or the caregiver to improve communication rather considering both parties as responsible for successful interaction. Future research could focus on ways to improve

communication techniques between caregivers and individuals with dementia as a dyad to reduce negative and improve positive outcomes.

Limitations

Several limitations exist within this study. First, attrition between the baseline and fifth waves resulted in a much smaller final sample size. However, this type of attrition is practically unavoidable considering the nature of the study. Many of the IWDs in the study were in a compromised physical state due to dementia and old age. As a result, several participants transferred to a long-term care facility or passed away over the course of the year (Kim et al., 2011).

Another limitation concerns the use of the WRB itself. Although the WRB contains fifty-three dementia related behaviors, none of the twelve categories address communication directly. Therefore, in order to use this dataset for the hypotheses, I had to construct my own communication measures out of the behaviors assessed in the WRB. Future studies that wish to investigate communication patterns between caregivers and IWDs should utilize questionnaires that target communication needs more directly. Erder et al (2012), recently presented a new measure of caregiver burden that examines communication patterns and social interactions between caregivers and IWDs. The Caregiver Perceived-Burden Questionnaire (CPBQ) was designed to measure these specific domains of function in IWDs and their effects on caregivers. Such a scale would be ideal to use for a future longitudinal study considering communication and caregiver burden.

Future studies might also consider observing caregivers and care-receivers to monitor interactions more directly. Such an approach could be employed to determine

how caregivers respond to types of communication exhibited by IWDs. This method would also eliminate reporting errors by caregivers regarding how frequently each communication item occurred.

Finally, the current study attempts to describe the aggressive and depressive communication behaviors exhibited by IWDs and does not assess the presence of communication disorders. Unfortunately, the Family CARES survey did not include information about the types of rehabilitation services each IWD received during the study, and the WRB does not contain information on IWD's communication disorders specifically. Thus, it proved difficult to assess particular aspects of the IWDs ability to communicate and, thereby, determine the particular therapy that would be most useful to IWDs in the study. Future studies of this nature should seek to obtain information about the participants' experience with speech therapy services.

BIBLIOGRAPHY

- Aggarwal, N., Vass, A. A., Minardi, H. A., Ward, R., Garfield, C., & Cybyk, B. (2003). People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing*, *10*(2), 187-197.
- Alden, Linda (06/01/2003). "Recognizing and coping with caregiver burnout". *Inside case management (1073-6514)*, *10* (6), p. 12.
- Aneshensel, C. S. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press
- Anthony, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of distress among caregivers of dementia patients. *Psychology and Aging*, *3*, 245-248.
- Banerjee, S., Willis, R., Graham, N., & Gurland, B. J. (2010). The Stroud/ADI dementia quality framework: a cross-national population-level framework for assessing the quality of life impacts of services and policies for people with dementia and their family carers. *International journal of geriatric psychiatry*, *25*(3), 249-257.
- Blackstone, S. (1996). The third thirty: Keep on communicating. *Augmentative Communication News*, *9*(2), 1-2.
- Bourgeois, M. S., Dijkstra, K., Burgio, L., & Allen-Burge, R. (2001). Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative Communication*, *17*(3), 196-196. Retrieved from <http://search.proquest.com/docview/220522428?accountid=13158>
- Bourgeois, M., Fried-Oken, M. & Rowland, C. (2010). AAC strategies and tools for persons with dementia. *ASHA Leader*, *15*(3), 8.
- Buller, N., & Ptok, M. (2005). Impairment of speech and communication skills in dementia. *Hno*, *53*(2), 177.
- Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., . . . Bankester, L. (2001). Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist*, *41*(4), 449-460. doi: 10.1093/geront/41.4.449
- Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*, *18*(12), 1006-1014.

- Derogatis, L. R., Lipman, R. S. & Covi, L. (1973). The SCL-90: An outpatient psychiatric rating scale. *Psychopharmacology Bulletin*, 9, 13-28.
- Dunkin, J. J., & Anderson-Hanley, C. (1998). Dementia caregiver burden A review of the literature and guidelines for assessment and intervention. *Neurology*, 51(1 Suppl 1), S53-S60.
- Egan, M., Bérubé, D., Racine, G., Leonard, C., & Rochon, E. (2010). Methods to enhance verbal communication between individuals with alzheimer's disease and their formal and informal caregivers: A systematic review. *International Journal of Alzheimer's Disease*, 2010, 1-12. doi:10.4061/2010/906818
- Erder, M. H., Wilcox, T. K., Chen, W., O'Quinn, S., Setyawan, J., & Saxton, J. (2012). A new measure of caregiver burden in alzheimer's disease: The caregiver-perceived burden questionnaire. *American Journal of Alzheimer's Disease and Other Dementias*, 27(7), 474-482. doi:10.1177/1533317512456449
- Farran, C. J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. *The Gerontologist*, 37(2), 250-257.
- Fauth, E. B., Zarit, S. H., Femia, E. E., Hofer, S. M., & Stephens, M. A. P. (2006). Behavioral and psychological symptoms of dementia and caregivers' stress appraisals: Intra-individual stability and change over short-term observations. *Aging and Mental Health*, 10(6), 563-573.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12(3), 189-198.
- Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989). Prevalence of depression in family caregivers. *The Gerontologist*, 29(4), 449-456. doi:10.1093/geront/29.4.449
- Germain, S (2009). "Does cognitive impairment influence burden in caregivers of patients with Alzheimer's disease?". *Journal of Alzheimer's disease (1387-2877)*, 17 (1), p. 105.
- Haberstroh, Julia (2011). "TANDEM: Communication training for informal caregivers of people with dementia". *Aging & mental health (1360-7863)*, 15 (3), p. 405.
- Hendryx-Bedalov, P. M. (2000). Alzheimer's dementia. coping with communication decline. *Journal of Gerontological Nursing*, 26(8), 20.
- Katzman, R., & Fox, P. J. (1999). The World-Wide Impact of Dementia. Projections of Prevalance and Costs. In *Epidemiology of Alzheimer's disease: From gene to prevention* (pp. 1-17). Springer Berlin Heidelberg.

- Kim, K., Zarit, S. H., Femia, E. E., & Savla, J. (2012). Kin relationship of caregivers and people with dementia: Stress and response to intervention. *International Journal of Geriatric Psychiatry*, 27(1), 59-66. doi:10.1002/gps.2689
- Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? what next? *The Gerontologist*, 37(2), 218-232. doi:10.1093/geront/37.2.218
- Lau, D.T., Berman, R., Halpern, L., Pickard, A.S., Schrauf, R., & Witt, W. (2010). Exploring factors that influence informal caregiving in medication management for home hospice patients. *Journal of Palliative Medicine*, 13(9), 1085-90
- Lawton, M. P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9, 179-186.
- Light, J. (1988). Interaction involving individuals using augmentative and alternative communication: State of the art and future research directions. *Augmentative and Alternative Communication*, 4, 66–82.
- Light, J. (1997). “Communication is the essence of human life”: Reflections on communicative competence. *Augmentative and Alternative Communication*, 13(2), 61-70.
- Littell, R. C., Miliken, G. A., Stroup, W. W., & Wolfinger, R. D. (1996). *SAS systems for mixed models*. Cary, NC: SAS Institute.
- Lubinski, R. (1995). *Dementia and communication*. San Diego, Ca: Singular Pub. Group.
- Miličević-Kalašić, Aleksandra (2009). “Caregivers care with Alzheimer’s disease, prevention of caregivers burn-out.” (pp. 67-71). Berlin, Heidelberg: Springer Berlin Heidelberg. doi: 10.1007/978-3-642-00326-4_5
- Nussbaum, J. F. (2000). *Communication and aging*. Mahwah, NJ: L. Erlbaum.
- Orange, J.B. (1991b). Perspectives of family members regarding communication changes. In R.Lubinski (Ed.), *Dementia and communication* (pp. 168–186).
- Orange, J. B., Van Gennep, K. M., Miller, L., & Johnson, A. M. (1998). Resolution of communication breakdown in dementia of the Alzheimer's type: A longitudinal.. *Journal Of Applied Communication Research*, 26(1), 120-138.
- Papastavrou, Evridiki (08/01/2011). "Caring and coping: the dementia caregivers". *Aging & mental health* (1360-7863), 15 (6), p. 702.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H. and Sourtzi, P. (2007), Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, 58: 446–457. doi: 10.1111/j.1365-2648.2007.04250.x
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990) Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.

- Rabins, P. V., Mace, N. L., & Lucas, M. J. (1982). The impact of dementia on the family. *JAMA : The Journal of the American Medical Association*, 248(3), 333-335. doi:10.1001/jama.1982.03330030039022
- Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.
- Rau, M. T., & National Council of Senior Citizens. (1993). *Coping with communication challenges in alzheimer's disease*. San Diego, Calif: Singular Pub. Group.
- Richter, Judith M. (10/1995). "Communicating with persons with Alzheimer's disease: experiences of family and formal caregivers". *Archives of psychiatric nursing (0883-9417)*, 9 (5), p. 279.
- Robinson, Karen M. (11/2001). "Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease". *Journal of advanced nursing (0309-2402)*, 36 (4), p. 573.
- Santo Pietro, Mary Jo. (2008). Assessing the communicative styles of caregivers of patients with alzheimer's disease. *Seminars in Speech and Language*, 15(3), 236-254.
- Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. (2005). Investigating the effects of communication problems on caregiver burden. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 60(1), S48-S55.
- Singer, J. D., & Willett, J. B. (2003). *Applied longitudinal data analysis: Modeling change and event occurrence*. Oxford: Oxford University Press.
- Small, J. A., Geldart, K., & Gutman, G. (2000). Communication between individuals with dementia and their caregivers during activities of daily living. *American Journal of Alzheimer's disease and other Dementias*, 15(5), 291-302
- Small, J. A., Gutman, G., Makela, S., & Hillhouse, B. (2003). Effectiveness of communication strategies used by caregivers of persons with alzheimer's disease during activities of daily living. *Journal of Speech, Language, and Hearing Research*, 46(2), 353-67. Retrieved from <http://search.proquest.com/docview/230791549?accountid=13158>
- Smith, M., & Buckwalter, K. (2005). Behaviors associated with dementia: Whether resisting care or exhibiting apathy, an older adult with dementia is attempting communication. nurses and other caregivers must learn to 'hear' this language. *The American Journal of Nursing*, 105(7), 40.
- Son, J., Erno, A., Shea, D. G., Femia, E. E., Zarit, S. H., & Stephens, M. A. P. (2007). The caregiver stress process and health outcomes. *Journal of aging and health*, 19(6), 871-887.

- Song, L., Northouse, L.L., Zhang, L., Braun, T.M., Cimprich, B., Ronis, D.L., & Mood, D.W. (2012). Study of dyadic communication in couples managing prostate cancer: a longitudinal perspective. *Psychooncology*, *21*(1), 72-81.
- Tellegen, Auke, D. Watson, & L. A. Clark. "Development and validation of brief measures of positive and negative affect: The PANAS scales." *Journal of personality and social psychology* *54.6* (1988): 1063-1070.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: the revised memory and behavior problems checklist. *Psychology and aging*, *7*, 622-622.
- Vitaliano, P. P., Russo, J., Young, H. M., Teri, L., & Maiuro, R. D. (1991). Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and aging*, *6*(3), 392.
- Williams, K. N., Herman, R., Gajewski, B., & Wilson, K. (2009). Elderspeak communication: Impact on dementia care. *American Journal of Alzheimer's Disease and Other Dementias*, *24*(1), 11.
- Young, T. J., Manthorp, C., Howells, D., & Tullo, E. (2011). Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing and Society*, *31*(6), 1003-1025.
doi:<http://dx.doi.org/10.1017/S0144686X10001182>
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of alzheimer's disease: Families under stress*. New York: New York University Press.

ACADEMIC VITA

Jeanna Stiadle
Jms6508@psu.edu

EDUCATION

Pennsylvania State University, University Park, PA Expected graduation 5/2014
Schreyer Honors College
College of Health and Human Development
Bachelor of Science
Major: Communication Sciences and Disorders
Minors: Vocal Performance, Human Development and Family Studies

The Ronald E. McNair Post-Baccalaureate Achievement Program Scholar
Cumulative GPA: 4.0/4.0

AWARDS AND GRANTS

Communication Sciences and Disorders Award, College of Health and Human Development,
Pennsylvania State University. Fall 2013-Spring 2014

Donato Trustee Scholarship, Schreyer Honors College. Fall 2011-Spring 2014

Bunton Waller Scholarship, Pennsylvania State University. Fall 2013-Spring 2014

Aramark Scholarship, ARAMARK Corporation. Fall 2010-Spring 2014

Mary Fox Scholarship, Montgomery Area High School. Fall 2010-Spring 2014

Renaissance Scholarship, Pennsylvania State University. Fall 2010-Spring 2014

Travel Grant, \$350, Schreyer Honors College. Summer 2013

Evan Pugh Scholar Award, Pennsylvania State University. Spring 2013

Internship Grant, \$750, Schreyer Honors College. Summer 2012

Sparks Award, Pennsylvania State University. Spring 2012

President's Freshman Award, Pennsylvania State University. Spring 2011

Dean's List Recognition, Pennsylvania State University, Fall 2010-Spring 2013

Phi Kappa Phi Honor Society Inductee, Pennsylvania State University, Spring 2013

High School Class valedictorian and president of National Honor Society, Spring 2010

RESEARCH

The Ronald E. McNair Post-Baccalaureate Achievement Program Summer Research Internship, *The Pennsylvania State University*, University Park, PA

Summer 2013

Completed an independent research project under the supervision of Dr. Steven Zarit
Presented research at the annual Penn State Summer Research Opportunity/McNair Research Conference

Currently preparing paper for publication, "Communication Problems Between Caregivers and Individuals with Dementia: Implications for Caregiver Well-Being"

Faculty Advisor: Dr. Steven H. Zarit, Human Development and Family Studies Department, Pennsylvania State University

Research Assistant, *The Pennsylvania State University*, University Park, PA

Spring 2012 - Present

Human Development and Family Studies Lab

Analyzes data using SPSS statistical software for various studies, all concerning older adults and dementia

Faculty Adviser: Dr. Steven H. Zarit, Human Development and Family Studies Department, Pennsylvania State University

Fall 2011-Fall 2012

Language and Literacy Research Initiative Lab

Coordinated and executed research studies investigating child development and speech language impairments

Faculty Adviser: Dr. Carol Miller, Human Development and Family Studies Department, Pennsylvania State University

Research Intern, *Temple University Infant and Child Lab*, Ambler, PA

Summer 2012

Assisted as a blind experimenter for a study on rhythm and regulation in children

Entered and analyzed data using Microsoft Excel and SPSS statistical software

Trimmed video data for analyses and edited transcriptions for recorded data

Adviser: Jessa Reed, Department of Psychology, Temple University

ORAL AND POSTER PRESENTATIONS

“Communication Problems between Caregivers and Individuals with Dementia: Implications for Caregiver Well-Being.” Poster presentation , Gerontological Society of America Conference, New Orleans, LA, November 22, 2013.

“Communication Problems between Caregivers and Individuals with Dementia: Implications for Caregiver Well-Being.” Presenter, SROP and McNair Research Symposium, Pennsylvania State University, PA, July 22-23, 2013.

“Communication Problems between Caregivers and Individuals with Dementia: Implications for Caregiver Well-Being.” Poster presentation, Undergraduate Research Exhibition, Pennsylvania State University, PA, March 18, 2013.

Stiadle, J. (2013). *Communication Problems between Caregivers and Individuals with Dementia: Implications for Caregiver Well-Being*. Poster presentation to be offered at Gerontological Society of America Conference (November).

PROFESSIONAL DEVELOPMENT

Ronald E. McNair Post-Baccalaureate Achievement Program Spring 2013 - Present

Participates in weekly professional development workshops and seminars related to graduate school preparation.

Fulfills program requirements, including maintaining a 3.0 GPA, enrolling in a research methodology course, and participating in a nine-week summer research internship.

College of Health and Human Development Honor Society Fall 2011-Present

President, Fall 2013-Present

Plans and leads networking and professional development meetings and events for over 200 society members

Presides over meetings with the executive board to delegate tasks for professional, social, and service events

Partners with other organizations such as the University Park Undergraduate Association(UPUA) and the American Red Cross to sponsor service initiatives

Secretary, Fall 2012-Spring 2013

Monitored attendance and dues for over 200 club members

Corresponded with members to resolve conflicts with meeting dates, due payments, and other concerns

Women’s Leadership Initiative Fall 2012-Present

Selected for this leadership program based on academic achievement, leadership potential, and service involvement

Attended professional development sessions throughout the year

Completed a separate service project as part of the program

National Student Speech Language and Hearing Association Fall 2010-Present
Penn State's Student Chapter of ASHA
Attends meetings for career development in Speech-Language Pathology
Completes at least one service activity per semester
Visits Hearthside nursing homes to provide social support to residents
Served as Team leader of Alzheimer Walk team (Fall 2013)
Helps sponsor a child fighting pediatric cancer as part of Penn State's PanHellenic Dance
MaraTHON

Penn State Opera Theatre Spring 2011-Present
Rehearsed and performed roles in various works including:
Amahl and the Night Visitors, Spring 2011
Gianni Schicchi, Fall 2011
The Tenderland, Spring 2012
Trouble in Tahiti Spring 2012
Bernstein's *Mass* Spring 2013
Dialogues of the Carmelites (2013)

Penn State Choral Ensembles Fall 2010-Fall 2012
Performed as a member of Essence of Joy Choir, Fall 2012
Performed as a Member of Oriana Singers, Fall 2010 - Spring 2012
Served as Soprano 1 Section Leader, Fall 2011 - Spring 2012
Performed as a Member of Discantus Chamber singers, Spring 2011

INTERNATIONAL EXPERIENCE

HDFS 597A—Aging in a Welfare State Summer 2013
Jönköping University and Karolinska Institute, Sweden
Two-week graduate course abroad about Sweden's social policy and rehabilitation services and how they pertain to older adults

WORK EXPERIENCE

Buddy Walk Coordinator Summer 2013-Present
Centre County Down Syndrome Society
Plans and manages all events for the 2014 Buddy Walk, a program to promote the inclusion and acceptance of people with Down Syndrome

Wedding Singer Fall 2006-Present
Leads singing at weddings in various local churches
Includes performances of choral and solo works

Certified Nursing Assistant Summer 2011-Spring 2012
Susquehanna Health System, Muncy Skilled Nursing Unit

Provided skilled care to residents in a nursing facility

SERVICE

Centre County Down Syndrome Society Performance Troupe Fall 2012 - Present

Music Director

Leads warm-ups and directs rehearsals for semi-annual musical revues

Plans and teaches choreography

Coordinated Homecoming Parade presentation

Penn State's Summer Day of Service and FRESHstart Spring 2013 – Fall 2013

Team Leader

Led incoming freshmen to complete two separate days of volunteer work

Summer Day of Service consisted of visiting a nursing home to provide

FRESHstart consisted of a daylong highway clean-up project

Penn State Special Olympics Spring 2013-Present

Event Volunteer

Annual 5K run fundraiser

Managed registration booth

Provided accommodations to runners

Summer Games

Provided assistance to participants

Assisted in event teardown

Penn State's Lifelink Spring 2012

Student Mentor

Assisted students with special needs to complete academic and career-related tasks

Engaged in activities with students to promote social well-being

Penn State's Pan-Hellenic Dance MaraTHON Fall 2011- Spring 2012

OPPerations Committee Member

Attended meetings throughout the year to prepare and raise funds for event

Assisted in hours of set-up and teardown for THON 2012

Cleaned and supplied bathrooms and stands of the Bryce Jordan Center for the duration of the 46 hour marathon