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Dementia: Incorporating Families And Caregivers In Direct Speech-Language Intervention

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DEMENTIA: INCORPORATING FAMILIES AND CAREGIVERS IN DIRECT SPEECH-LANGUAGE INTERVENTION

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DEDICATION

This thesis is dedicated to my parents
John and Kaye Hartley, for their
unfailing love and encouragement.

To my Heavenly Father, whose love never runs out on me.

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ABSTRACT

In a survey, 50% of 1,000 caregivers reported that they received no information on dementia at the time of diagnosis (Thompson & Pulsford, 2012). This statistic provides strong evidence as to why caregivers feel ill-prepared to care for individuals with dementia. The role of a speech-language pathologist (SLP) is suggested to not only treat the individual with dementia, but consider the role and perspective of the caregiver (Watson, Aizawa, Savundranayagam & Orange, 2013). Providing education and training to caregivers of individuals with dementia is within the scope of practice of speech-language pathologists (Watson et al., 2013).

A survey design for the current study examined SLPs' attitudes of incorporating family members and caregivers into therapy with individuals with dementia. A web survey was submitted to seek participants. Intermittent descriptive texts were included in the survey to allow SLPs to comment further on their responses.

Fifty-nine SLPs completed the survey. All participants reported providing communication training/counseling to family members and caregivers of individuals with dementia. SLPs reported observing a positive difference in the individuals with dementia and both care provider groups when incorporated into therapy. However, limitations such as "availability of the care provider" and "time" were ranked as high factors prohibiting inclusion. Overall, results of the current study suggest that incorporating and providing communication training/counseling to both care provider groups has positive outcomes.

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CHAPTER 1

INTRODUCTION

What is Dementia?

Dementia is a ‘syndrome’ characterized by a deterioration in cognitive function and memory (Brookshire, 2015; Chapey, 2008). The cognitive decline is sustained over a period of months or years and is severe enough to interfere with activities of daily living (Brookshire, 2015; Chapey, 2008). The deterioration in cognitive function is most notable for the decline in memory (Chapey, 2008). Memory is stored representation comprised of multiple systems that are interrelated (Chapey, 2008). It can be divided into three categories including short term memory, long term memory and lexical memory (Watson & Shadowens, 2011). In a brain effected by dementia, items or events will not be recalled from memory-as if it never happened (Watson & Shadowens, 2011).

Dementia diagnosis is determined by a physician (Watson & Shadowens, 2011). General guidelines for the diagnosis emphasize a cognitive decline over a period of six months is required (Watson & Shadowens, 2011). During the diagnostic process, families and caregivers play a key role in providing the physician observed functional changes that may be related to dementia (Watson & Shadowens, 2011). In part, this is due to the individual under consideration for a dementia diagnosis not being a reliable reporter of ability or deficits. Functional changes could include declines in ability to concentrate, ability to self-feed, behavioral changes, ability to communicate and decreased coordination (Watson & Shadowens, 2011). Understandably, these functional changes might increase the level of care needed for individuals with dementia. In so doing, that increased level of care may increase the burden for family and caregivers who may be struggling to understand the changes themselves.

According to the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; American Psychiatric Association, 1994) to obtain a diagnoses of dementia, an individual must exhibit the following:

1. Impaired short term memory,
2. Impaired long-term memory, and
3. At least one of the following characteristics: impaired abstract thinking, personality change, impaired judgment, impaired constructional ability, impaired language, impaired praxis or impaired visual recognition (DSM-IV, 1994).

Physicians compile multiple information sources to determine if observed functional changes are caused by dementia, normal aging, or a pseudo dementia (Watson & Shadowens, 2011). Family and caregivers are important in assuring reports of functional performance are consistent with consideration for performance in multiple settings and activities (i.e., home, community, self-help, leisure).

Caring for individuals with dementia within all settings require communication skills and strategies (Eggenberger, Heimerl & Bennett, 2013). Communication difficulties are one of the distinct features perceived as stressful by caregivers of dementia whether informal or formal (Eggenberger et al., 2013; Watson et al., 2013). Identifying how caregivers improve their communication strategies would appear critical to assuring competent care for individuals with dementia.

Quality of life (QoL) is strongly influenced by a person's ability to communicate (Haberstroh, Neumeyer, Krause, Franzmann & Pantel, 2011). Communication is fundamental human attribute that enables personal and social engagement. Individuals who exhibit decreased communication abilities may feel excluded and withdrawn from the social world (Haberstroh et al., 2011). Dementia includes an expected and significant language deterioration that has negative rippling effects including relationship and communication breakdowns (Balkanska, 2012). As the severity of dementia increases, the individual's language inability follows suite (Watson et al., 2013). It is essential to maintain or adapt communication for individuals to preserve their QoL (Haberstroh et al., 2011).

It was estimated that 500,000 new cases of dementia were diagnosed in the United States during the year of 2015 (Hopper, Douglas & Khayum, 2015). According to a survey, 15% of a speech-language pathologist's (SLP) caseload was working with individuals diagnosed with dementia in healthcare settings (Hopper et al., 2015). These statistics indicate the probability that there are many family and caregivers who could potentially benefit from the expertise of speech-language pathologists to provide effective communication training. However, many family and caregivers do not receive information on how to access assistance from a speech-language pathologist (Lubinski, 2003). Therefore, family and caregivers typically receive little training and support to enable them to meet specific communication needs of people with dementia (Eggenberger et al., 2013; Jennings et al., 2015). The following study examines dementia service provision by SLPs and inclusion of caregivers in that service.

CHAPTER 2

LITERATURE REVIEW

Effects of Dementia on Family Members

Caring for the individuals with dementia is challenging (Watson, Aizawa, Savundranayagam & Orange, 2013). Simpson and Carter (2013) found that a family member spent an average of 80 hours per week caring for an individual with dementia. In a survey of 1,181 family member participants within five countries; Germany, Poland, France, Scotland, and Spain, Georges and colleagues (2008) reported that in a 24-hour period, 14 hours on average were spent providing direct care. Due to the significant burden of time spent caring for an individual with dementia, a financial impact may occur (Georges et al., 2008). In fact, Simpson and Carter (2013) revealed that 41% of family members still employed reduced their work hours in order to accommodate time to provide care. This life-style adjustment is just one of the multiple effects dementia has on the family member.

Simpson and Carter (2013) surveyed 80 residential and nonresidential family members to explore how problematic behaviors of a person with dementia affects the caregiver's sleep. The authors revealed that a significant complaint for a family member is lack of sleep. They reported that many reasons contribute to their lack of sleep. The first is caregivers' decision to complete house chores during typical sleeping periods. Responses on the Pittsburgh Sleep Quality Index (PSQL; Buysse et al., 1989) indicated caregivers replaced sleep with chores including cleaning and paying bills. These activities reportedly cannot be completed while the individual with dementia is awake due to an increased need for care and attention. Next, the authors reported that caregivers lose sleep because of excessive worrying about caregiving. The caregiver may worry and ruminate because behaviors exhibited by the individual with dementia are inconsistent with prior behaviors displayed before the dementia diagnosis. Finally, sleep may be disrupted due to night time interruptions by the person with dementia. Interruptions included assisting the person with dementia to the bathroom and being awakened by a confused or disoriented individual. These disruptions were reported to occur three or more nights per week. Losing sleep continuously can become a perpetuating factor that could result in chronic insomnia or other sleep disorders (Simpson & Carter, 2013).

Perren, Schmid and Wettstein (2006) stated that problematic behaviors may lead to caregiver stress. They suggested that behavior problems are the primary predictor for caregiver's well-being. The authors examined the effects of a psycho-educational group intervention on family members' well-being as they care for individuals with dementia. The study included 128 dyads of care recipients and family members. Among the participants, 90% of family members were spouses of the individual with dementia. Sixty-five dyads were randomly selected for the intervention group and 63 for the control group. Intervention consisted of eight weekly sessions, targeting an increased education of dementia symptoms, strengthening family members' self-care and self-perception, optimizing the relationship between the caregiver and individual with dementia, and providing a social support group. Interviews with family members two-years post intervention indicated behavior problems of individuals with dementia increased. However, caregivers within the intervention group reported a stable sense of wellbeing. These participants were less likely to be affected negatively by the behavioral problems. In contrast, the participants in the control group demonstrated a decreased well-being. A rate of change in cognitive and functional impairments in addition to increased behavior problems were found to be contributing factors to a decreased well-being.

As cognition deteriorates, an individual's ability to self-feed and safely swallow also declines (Watson & Shadowens, 2011). In a caregiver's guide, "Dementia: Loving Care with a Therapeutic Benefit" deglutition problems was an indication of dementia advancement (Watson & Shadowens, 2011). The deterioration in the ability to safely swallow increases the risk for aspiration. The decline in deglutition is characterized by multiple factors. First, as dementia progresses, oral sensations decrease. This results in a reduced awareness of food present in the mouth. An individual with dementia may pocket food in the mouth, creating a safety issue. Pocketing food may occur due to the individual with dementia forgetting to chew or not sensing that they have food in their mouth. This may lead to food going down the throat and/or airway unintentionally, increasing the chance of choking or aspirating. In addition, temperature sensation for food declines, elevating a risk for the individual to burn oral and pharyngeal tissues. Atypical behaviors while eating also become prominent according to Watson and Shadowens. These behaviors could include leaving the table, using their fingers to eat rather than utensils, and playing with their food. It is not uncommon for an individual with dementia to exhibit anxiety during mealtime. Reportedly, this may be due to overstimulation from noises and visual distractions in the kitchen and at the table. Individuals may find the presence of the food on their plate confusing or overwhelming in later stages of dementia. Too many utensils placed in front of them may be over-stimulating or over-whelming in the inability to make a selection. The anxiety and need to eliminate the stimulation may result in the individual leaving the table prior to completing the meal. Wandering (aesthesia) in response to over-stimulation is not an uncommon characteristic of dementia.

Watson and Shadowens (2011) stated that family members will experience a full range of emotion. A family member may feel unprepared for the daily unknowns. McKay (2013) stated, “It takes courage, flexibility and willingness to change and to grow to be an effective caregiver” (p. 272). The willingness to be flexible is an important aspect for a caregiver (McKay, 2013). Understandably, burnout is a frequent occurrence among family members (Jennings et al., 2015). Burnout is a state of emotional and physical exhaustion that erodes mental health (Passalacqua & Harwood, 2012). Caregiver burnout is due to the disease’s effect on behavior, personality, communication and cognition of the individual with dementia (Jennings et al., 2015). It ultimately becomes too overwhelming, exhausting and strenuous for family members to manage and adapt to the progressive changes (Jennings et al., 2015). Supervision and personal care for the individual with dementia increases as they become more dependent on the family member, increasing the physical burden of care (Jennings et al., 2015). These stressful aspects lead to an increased risk for depression, cardiovascular disease and mortality for a family member (Jennings et al., 2015; Samia, Hepbourn, & Nichols, 2012). In addition, an elevated level of strain and burnout lead to a higher rate of nursing home placements for individuals with dementia (Jennings et al., 2015). However, despite negative factors contributing to caregiver burnout, Jennings and colleagues (2015) encouraged that it is important for the caregiver to learn how to manage and be flexible through these progressive changes. Increased management and flexibility may reduce the caregiver's strain and burnout that could disrupt their employment and deplete finances.

Effects of Dementia on Caregivers

Providing professional, quality care to individuals with dementia is not an easy task whether informal or formal (Barnes, 2012). Caring for individuals who exhibit disruptive behavior symptoms of dementia is challenging (Enmarker, Olsen, & Hellzen, 2010; Kuske et al., 2009). Behavior disturbances in individuals with dementia are characterized as a "pendulum" between a loss of power and capability (Enmarker, et al., 2010). Many reasons that contribute to aggressive or agitated behavior have been identified (Barnes, 2012; Enamrker et al., 2010). Reasons identified include decreased communication ability, premorbid personality, and misinterpretation of the environment by the individual with dementia (Barnes, 2012; Enamrker et al., 2010).

In a systematic literature review, Enmarker and colleagues (2010) examined 21 articles published between 1999-2009, which focused on people with dementia who acted violently and aggressively in a nursing home. The purpose was to describe aggressive and violent behaviors of a person with dementia from the perspective of a nurse employed in a nursing home. The authors recognized personal care as the primary source for behavior disturbances. Specifically, morning personal care by a nursing staff such as washing, dressing and grooming appeared to be the main services resulting in aggressive behaviors. Personal care services require a high degree of intimate touch and physical manipulation that may cause physical pain or feelings of violation (Barnes, 2012; Enmarker et al., 2010). One way for a person with dementia to communicate or respond to that pain or fear is through gripping, hitting and irritability (Barnes, 2012; Enmarker et al., 2010). These behaviors stem from a person's inability to directly communicate his or her needs and perhaps, some degree of loss of independence (Barnes, 2012; Enmarker et al., 2010; Vasse et al., 2010).

Enmarker and colleagues (2010) found that depression and premorbid personality were a significant cause of aggression. Approximately 50% of seniors 85 years or older living in a nursing home with dementia were reported to demonstrate depression. Reportedly, an individual's premorbid personality may be linked to aggression. Individuals with premorbid personalities typically have experiences that include domestic violence and drug use. According to the authors, when individuals with personality disturbances or addictive histories grow older and experience dementia, their violent tendencies increase. They continue to act aggressively and violently toward their caregivers.

Barnes (2012) reported residents with dementia may misinterpret their environment. If their surrounding is noisy, over-stimulating or chaotic, they may demonstrate fear and agitation. For example, an individual with dementia may hear a voice coming from the television, but not recognize from where it is coming. In response, they may talk back to the voice. If the voice from the television is angry, the individual's response may mirror that anger. Barnes suggested that during these moments, individuals with dementia may not recognize their current environment. This is due to decreased orientation to place and time due to short-term inability to problem solve.

Another reason as to why caring for individuals with dementia is difficult for caregivers is burnout – the state of emotional and physical exhaustion (Passalacqua &

Harwood, 2012). Burnout among caregivers is reportedly high due to the demands associated with caring for individuals with dementia (Paasalacqua & Harwood, 2012). Caregiver burnout leads to high employment turnovers and vacancies. Four 1-hour workshops discussing person-centered care was provided to 26 paraprofessional caregivers. Following the fourth workshop, an anonymous evaluation was administered to gather feedback and assess perceived usefulness of the workshops. Results of the evaluation determined three hallmark burnout characteristics: patient depersonalization, emotional exhaustion, and reduced sense of personal accomplishment. They indicated these characteristics result in a decrease in the quality of care provided a person with dementia.

Communication Difficulties between Caregivers and Individuals with Dementia

Many have examined the communication breakdowns that occur between the caregiver and the individual with dementia as the disease progresses (Haberstroh et al., 2011; Purves & Phinney, 2013; Small & Perry, 2013; Watson et al., 2013). Small and Perry reported that family members usually have a long-standing history of interactions with the individual with dementia that include habits and patterns of interaction. These interaction habits were given little thought until the illness began to impact the communication between the caregiver and individual with dementia. Skills relied on and familiar to the family members were no longer adequate to assure successful exchanges (Small & Perry, 2013).

Purves and Phinney (2013) conducted a qualitative study that followed two Canadian families, each with a family member diagnosed with Alzheimer's disease or primary progressive aphasia. Eleven family members in total participated in three data collection systems. Data collection systems included a semi-structured interview with the author, daily conversation audio or video recording between a family member and the individual with dementia, and observation of interactions made by the authors. Significant themes were identified among the families that revealed a sense of loss and frustration due to the communication breakdowns. Another theme identified was that the participants continuously made conscious efforts to maintain conversation with the person with dementia.

Consequently, communication breakdowns may trigger behavior problems including yelling or agitation (Watson et al., 2013). Watson and colleagues reported that these problem behaviors may stem from word retrieval problems (anomia), the need to engage in activities, inability to express feelings or inability to understand verbal instructions. Usually, a pattern of frequent communication breakdowns results in increased problem behavior issues (Haberstroh et al., 2011; Watson et al., 2013). In essence, these behaviors significantly contribute to caregiver burden and stress (Watson et al., 2013).

Effective communication is essential for assessing the individual needs of residents and to better understand a family's perspective (McGilton et al., 2009). In general, effective communication is a clear link to improved quality of life and well-being of residents (McGilton et al., 2009). In many residential care facilities, caregivers may be the only source of social interactions for individuals with dementia (McGilton et al., 2009). Building strategies for improved communication supports caregiving. Once effective communication has been achieved, the individual with dementia is more likely to remain calm, anxiety-free while demonstrating increased dialogue with their caregiver (Elkins, 2011). It also may enable a more familiar routine for each.

Communication Training

As reported previously, family members caring for an individual with dementia report facing multiple challenges in providing care (Eggenberger et al., 2013). Communication issues were linked to many of the problems. A lack of knowledge of dementia symptoms, specific changes in communication, and methods to achieve effective communication are common sources for caregiver challenges (Eggenberger et al., 2013). Methods to facilitate meaningful interactions in dementia care and educate caregivers are provided in the literature (Eggenberger et al., 2013).

Communication training: Family-centered approach.

A family-centered approach is one method to facilitate meaningful interactions in dementia care (Purves & Phinney, 2013). Purves and Phinney stated that communication is not confined solely to caregivers and individuals with dementia; it is an integral part of every relationship within the family. Family-centered approaches include counseling and helping families develop more effective communication from their perspective. Goals seek to identify the communication impairments among individuals with dementia that disrupt the complex family dynamic and roles. It acknowledges that each family member can bring new insight into the problems they face and provide resources to address the issues. An emphasis on counseling the family in coming to terms with the loss associated with communication impairments is included. Furthermore, Purves and Phinney identified that a family-centered approaches help identify how different family members can contribute in supporting the conversation needs of the family as a whole.

Communication training: A person-centered approach.

A person-centered approach has also been identified as a method to facilitate meaningful interactions with individuals with dementia (Passalacqua & Harwood, 2012). The approach includes four elements: valuing the person with dementia and their caregiver, recognizing the individuality of the person with dementia, acknowledging the perspective of the person with dementia, and promoting a healthy environment (VIPS). Passalacqua and Harwood implemented this approach with 26 paraprofessionals caring for individuals with dementia in a long term-care facility. Following training, the results demonstrated positive outcomes for residents and paraprofessional caregivers. In particular, the paraprofessionals reported less depersonalization of residents and more empathy. Specific communication strategies increased including yes/no questions, using more gestures and giving the choice between two options. The paraprofessionals increased their perspective regarding dementia, recognizing that improvements and adaptations are possible. Training was reported to be helpful and beneficial. Overall, Passalacqua and Hartwood identified that paraprofessional burnout decreased following implementation of a person-centered approach among paraprofessionals.

Communication Training: Direct and Indirect Intervention

Hopper, Douglas and Khayum (2015) described a direct intervention approach for individuals with dementia. Direct intervention is focused on maintaining residual communication strengths. It provides the individual with dementia with skill training that incorporates the use of external communication and memory aid. These types of external aids may enhance communication exchange and assist in maintaining daily schedules and information. Examples of memory aids include memory books, which demonstrate positive cognitive and communication outcomes. Another example includes spaced-retrieval training and errorless learning, which have also shown promising outcomes (Bourgeois, 2009; Hopper et al., 2015). The researchers reported that direct intervention can be implemented with a client individually or in a group (Hopper et al., 2015).

According to Egan, Berube, Racine, Leonard and Rochon (2010), external memory aids combined with caregiver communication training was effective in improving participants' discourse related to a particular topic. A literature review investigated effective methods used to improve verbal communication of individuals diagnosed with Alzheimer's disease with their caregivers. Thirteen studies were included in the review. Positive outcomes due to the incorporation of an external memory aid in conjunction with communication with individuals with Alzheimer's disease included an increased topic maintenance, increased time spent on topic, increased words per topic and fewer topic changes. However, results demonstrated that memory aids did not appear to encourage generalization to other conversation topics.

Indirect interventions include a focus on the social, physical and attitudinal environment of an individual diagnosed with dementia (Hopper et al., 2015). These approaches primarily incorporate the family member and caregiver training to promote communication opportunities (Egan et al., 2010; Hopper et al., 2015). For example, TANDEM is an example of indirect intervention (Haberstroh et al., 2011). This program incorporates family members by deepening their individual strategies to support remaining strengths in individuals diagnosed with dementia. The goal of the program is to increase quality of life (QoL) of the individual with dementia and reduce caregiver burden. Haberstroh and colleagues conducted a training program incorporating 24 family members during a five-week period. The structure of the training program was set by the TANDEM model which included the expertise of geriatric psychiatry, geriatric care and educational psychology. The goal was to deepen family member communication competency to support the individual with dementia's remaining communication strengths. The training was evaluated using pre and post control design and time-series analysis. The individuals with dementia QoL measurements were obtained before and after the intervention using proxy reports by caregivers. The results of the study indicated that TANDEM training increased the individuals' with dementia QoL in the intervention group compared to the control group. Caregivers were given standardized diaries to monitor their use of strategies and self-reflect on their behavior output. Results showed that the intervention increased communication strategies used by family members. However, the study could not identify a reduction of caregiver burden following the intervention.

Similar programs are designed to teach caregivers tailored strategies to improve communication (Egan et al., 2010). Such programs rely on "conversation analysis" which assists caregivers in identifying and addressing effective and non-effective conversation techniques (Egan et al., 2010). Analyses of conversation include turn-taking, interaction, topic maintenance and resolving communication breakdowns.

Hopper and colleagues (2015) examined two case studies of two individuals diagnosed with Alzheimer's disease and dementia. The goal was to determine if the combined treatment facilitated communication for the individual with dementia and increased their QoL. The QoL was determined by portions of the Environment and Communication Assessment Toolkit for Dementia Care (ECAT; Brush, Calkins, Bruce & Sanford, 2012) completed by Certified Nursing Assistants (CNA) who interacted with the participants regularly. The authors implemented a combined treatment program of direct and indirect approaches for each participant. The first participant, diagnosed with Alzheimer's disease, used an external aid such as an iPod to assist them in managing household activities and daily schedule. The second participant, diagnosed with dementia, indirectly photographed events, people and objects in the long term-care facility. Photography provided the participant with numerous conversation opportunities. Results indicated that a combination of both direct and indirect approaches facilitated communication and increased the QoL in the two participants. The authors concluded that the participants' QoL increased as shown by a rise of participation in naturalistic activities and communication opportunities. Concluding the study, the first participant was able to meet four out of five therapy goals. In addition, the second participant increased socialization target by at least 50 percent. Hopper and colleagues recommended that in order for a combination of direct and indirect therapy to be successful, it should be person centered and culturally appropriate.

Communication training: Collaborative intervention vs. individual intervention.

Neely, Vikstrom and Josephsson (2009) examined the significance of collaborative intervention compared to individual intervention among individuals with dementia. Collaborative intervention was described as a caregiver or spouse working together with the individual diagnosed with dementia to acquire and practice supported memory strategies that can encourage social interaction. Fifteen participants diagnosed with mild to moderate Alzheimer's disease or vascular dementia along with their spouses participated in the study. The participants were divided into either a collaborative program, individual program or control group. In the collaborative program, intervention focused on space retrieval and hierarchical cueing. The partner was encouraged to provide verbal guidance that would be best understood by the person with dementia. The tasks for this group was to recall objects in random order and category clusters. In the individual program, the participant received the same intervention but without the presence of a spouse or caregiver. The tasks for this group included recalling non-categorical words and categorical words. The control group did not receive intervention. Results showed that recall performance of individuals with dementia in the collaborative group increased from pre-test and post-test in both random and clustered tasks. For the random task, the mean number recall increased from 2.0 to 4.5. The mean number recall increased from 3.3 to 5.3 for the clustered task. However, individuals with dementia in the individual group decreased recall performance. The mean number recall decreased from 3.1 to 2.2 for the random task and decreased from 3.8 to 3.5 for the cluster task.

Overall, the participants with dementia improved episodic memory in the collaborative group compared to the participants in the individual and control group (Neely et al., 2009). Results indicated that active participation of the caregiver in the collaborative groups matters in cognitive rehabilitation (Neely et al., 2009). A collaborative program creates a stimulating and challenging learning context for the individual with dementia and the presence of a caregiver or spouse increases social interactions (Neely et al., 2009).

Effects of Communication Training and Education

The following studies have examined the effectiveness of communication training for individuals with dementia and their care providers, both family member and caregiver (Eggenberger et al., 2013; Haberstroh, 2011; Harley, Reid & Burnham, 2010; Watson et al., 2013). A variety of improvements were found including reduction in caregiver burden, increased caregiver perspective, increased behavior and enhanced QoL for both the caregiver and individual with dementia.

Watson and colleagues (2013) reviewed seven studies from 1999-2011 that incorporated communication strategy training to family members and individuals with dementia. Collectively, the studies demonstrated that individualized education and training that targets specific communication enhancement strategies, reduce caregiver burden. In addition, depersonalization decreased, which corresponded to an increase in

QoL for patients with dementia. The authors described that family members often perceive communication breakdowns as lonely and frustrating.

Eggenberger and colleagues (2013) identified increased quality of care provided by caregivers to individuals with dementia following communication training. The authors completed a literature review to evaluate interventions that have been designed to enhance communication in dementia care in any setting. Twelve studies, totaling 831 persons with dementia, 519 caregivers and 162 family members residing in the United States, United Kingdom and Germany were included in the review. Results showed an increased QoL in individuals with dementia in nursing homes and home-care settings following communication skills training. The researchers stated that the results demonstrated a clear benefit for the person with dementia evidenced by enhanced positive behaviors and satisfying interactions. The communication skills training increased the caregivers' and family members' awareness of the perspective of the individual with dementia. This new perspective helped construct an understanding of challenges and opportunities for communication with individuals with dementia. Caregivers reported an increased feeling of being in control and enjoyed the opportunity to learn more about the patient they cared for. Overall, the communication skills training increased caregiver and family member communication skills, competency and knowledge.

Zientz, Backley and Chapman (2007) concluded from a literature review on seven studies that education on communication strategies positively affected job satisfaction for caregivers. The purpose of the review was to evaluate studies that educate caregivers and family members about dementia and provide communication enhancing strategies. Results indicated that turnover rates for caregivers were significantly less six months following training. Furthermore, even minimal changes in interaction behaviors positively affected QoL in individuals with dementia. An increased amount of encouragement and a decreased amount of criticism was used when interacting with individuals with dementia. Therefore, residents with dementia showed a reduction in symptoms of depression, irritability, and aggression. Similar conclusions were found in a literature review by McGilton and colleagues (2009). They found that implementing a communication training increased caregiver communication skills, behavior and knowledge. Staff reportedly increased the use of positive statements and provided more information to residents. Following training, staff were rated using various observational behavioral measures as more involved, warmer, and less patronizing towards residents. These behavioral changes by the caregivers resulted in increased responsiveness and eye contact from the individuals with dementia as well as decreased verbal disapproval, anger and agitation.

McGilton and colleagues (2009) conducted a literature review to determine the effect of communication interventions targeting caregivers such as CNAs and nurses, who care for residents in a long-term care facility regularly. Four out of the six articles were comprised of resident participants with dementia. Based on the results, the authors recommended that communication training be multilevel to increase caregiver communication exchange with individuals with dementia in long-term care facilities. In particular, they suggested the training be composed of three components: educational training, practice and support. Education is directed at providing staff with increased knowledge regarding effective communication techniques that are specific to their resident's communication impairments. The goals encompassed interaction strategies and behavior management strategies. Generalization of the learned communication behaviors focused on incorporating practice of instructed communication and behavior management techniques. Providing support for staff to incorporate learned strategies in interactions was reported as vital. The authors suggest incorporating a psychological component when providing support to staff. This includes supervisors providing positive feedback and encouraging self-reflection of new practice.

Using effective communication skills with individuals with dementia would seem far easier in theory than in practice (McEvoy & Plant, 2014). Evidence supports that family members and caregivers likely require training and supervision to support them in developing their skills (McEvoy & Plant, 2014). Additionally, it is recommended they receive comprehensive information on dementia, its treatment and relevant support services in order to provide efficient care (Georges et al., 2008).

Lack of Communication Training and Education

Despite the awareness that training has positive outcomes, caregivers and family members typically receive little training or support to enable them to meet specific communication needs of people with dementia (Eggenberger et al., 2013; Jennings et al., 2015). This results in the healthcare professionals unprepared to address the complexities of caregiving for individuals with dementia to caregivers (Jennings et al., 2015). Georges and colleagues (2008) found that 50% of 1,000 family members reported that they received no information on dementia at the time of diagnosis. In addition, 66% of those participants received no information regarding the disease process. Eight-two percent reported information regarding available services was not provided. In addition, Balkanska (2012) identified that 43% of 181 family members in a study stated they were not informed about the realities of dementia. These statistics provide strong evidence as to why caregivers feel ill-prepared to care for individuals with dementia (Watson et al., 2013).

In addition to the evidence that caregivers lack knowledge of dementia and methods to achieve effective communication, many caregivers do not receive information on how to access assistance from a speech-language pathologist (Eggengerger et al., 2013; Georges et al., 2008; Lubinski, 2003; Watson et al., 2013). According to a survey, 15% of an SLP’s caseload in healthcare settings is working with individuals diagnosed with dementia (Hopper et al., 2015). Additionally, it was estimated that 500,000 new cases of dementia were diagnosed in the United States during the year of 2015 (Hopper et al., 2015). These statistics indicate the probability that there are many caregivers who could potentially benefit from the expertise of speech-language pathologists to provide effective communication training.

The Role of Speech-Language Pathologists in Dementia Care

Speech-language pathologists are in an optimal position of adopting emerging therapy interventions and counseling for all populations and communication disorders (Watson et al., 2013). Watson and colleagues confirmed that providing education and training to caregivers of individuals with dementia is within the scope of practice of speech-language pathologists. As a dynamic communication disorder, dementia requires speech-language pathologists to look further than evidence-based practice interventions and adopt a more holistic-based perspective (Watson et al., 2013). An increased holistic-based perspective encourages looking further than the individual with dementia exclusively to include the role and perspective of the caregiver.

Researchers have provided suggested guidelines for speech-language pathologists to follow when providing communication training to family members and caregivers. Eggenberger and colleagues (2013) stated that communication training should not be perceived as a single-dose intervention. Rather, it should include a periodic “booster”. This booster would allow speech-language pathologists to provide both family members and caregivers a chance to ask questions and receive feedback about communication strategies. Zientz and colleagues (2007) recommended administration of education and training in at least four sessions. These individual sessions or conferences would be committed to discussing individual concerns and to provide direct feedback on communication interactions. The desired outcome for the caregivers would include increased knowledge of dementia and communication problems, increased knowledge on the use of communication strategies, and increased communication satisfaction. Perhaps more importantly, for individuals with dementia, results of training could have positive effects on the amount and types of communication.

Lubinski (2003) stated that caregiver training should include a two-pronged approach. The first prong includes information giving. Lubinski clarified that even though family members want information, they do not want a lecture more suitable for professionals. It is important that speech-language pathologists find a balance for the depth of information they provide. A list of “Do’s or Don'ts'” regarding communication management is not recommended. Instead, she encouraged speech-language pathologists to aid family members in problem-solving situations they encounter. The second prong includes emotional support. Speech-language pathologists cannot avoid discussing the emotional impact of communication breakdowns. This prong allows the caregiver to acknowledge and cope with their feelings which is essential to more effective communication.

It is unrealistic to assume that the primary health care provider can provide all the information and services regarding dementia alone (Jennings, et al., 2015). A multi-disciplinary team approach should be in place to broaden dementia education and management (Jennings et al., 2015). Access to a nurse practitioner, dementia care specialist, or an interdisciplinary team including pharmacist, physical therapist, occupational therapist and speech therapist can increase the chance that caregivers receive comprehensive information and support (Jennings et a., 2015). Primary health care professionals need to be aware of the expertise of the speech-language pathologists so that referrals can be made (Lubinski, 2003). At the same time, speech-language pathologists need to be more accessible to caregivers (Lubinski, 2003). Research has supported just how valuable communication training to a caregiver is by demonstrating a range of positive effects (Jennings et al., 2015).

Statement of the Problem

Purves and Phinney (2013) found that 80% of 101 speech-language pathologists in Canada indicated that they offer or always provide education to caregivers. However, the study did not differentiate between family members and caregivers. This was found to be a trend in speech-language pathology literature. Research demonstrates positive effect of incorporating the caregiver into therapy for the individual with dementia, but did not distinguish the positive effects by provider groups (Neely, Vikstrom & Josephsson, 2009). Additionally, the perspective of the speech-language pathologists incorporating caregivers into therapy with individuals with dementia is lacking. The present study examined the following questions:

1. Do speech-language pathologists incorporate family members and /or caregivers into therapy with individuals with dementia?
2. Do speech-language pathologists report providing communication training and/or information to family members and/or caregivers of individuals with dementia?
3. What perspectives do speech-language pathologists report with regard to incorporating family members and/or caregivers into therapy with individuals with dementia?
4. What limitations, if any, do speech-language pathologists report involving family members and/or caregivers into therapy?
5. If family and caregivers are incorporated into therapy, what methods do speech-language pathologists use to train them?

CHAPTER 3

METHODS

This chapter will describe the participants, procedures, and data analyses comprising the methodology. The study was approved through the Eastern Kentucky University Institutional Review Board.

A survey design was chosen to examine current clinical practices of speech-language pathologists (SLPs) working with individuals diagnosed with dementia and their family members or caregivers. In particular, the purpose of the survey was to gain perspective from the SLPs regarding incorporation of family members or caregivers into direct therapy with individuals diagnosed with dementia. The survey design permitted quantitative descriptions of trends and attitudes of the sample population (Creswell, 2014).

Participants

Inclusion criteria for participants were: (a) speech-language pathologist with a Master's degree, (b) state licensure and certification by the American Speech-Language-Hearing Association (ASHA), and (c) at least one year of experience working in one of the following settings: skilled nursing facility, private practice, nursing home facility, home health, or other medical setting. A single-stage recruitment design was chosen (Yu & Cable, 2014). To identify potential respondents, a recruitment letter (Appendix A) was posted on multiple modalities in October 2016. The recruitment letter included the purpose of the survey, participant criteria, relevant contact information, and URL link to the survey. A statement regarding the participant's anonymity during all stages of the research study concluded the recruitment letter. The letter was published to three professional special interest (SIG) listservs of the American Speech-Language-Hearing

Association (ASHA) including SIG 2: Neurophysiology and Neurogenic Speech and Language Disorders, SIG 13: Swallowing and Swallowing Disorders Dysphagia, and SIG 15: Gerontology. These listservs were chosen as relevant to the research topic and an increased likelihood of eligibility for participant responses. In addition, the letter and survey were posted to a private online discussion board. Respondents were permitted to complete the survey questionnaire from October 2016 to December 2016.

Procedure

A 16-item survey instrument was created by the principle investigator (PI) to collect data regarding the perspective of the SLPs' frequency and attitude of incorporating family members and caregivers into direct speech therapy services with individuals diagnosed with dementia (Appendix B). Questions were developed following review of current research literature on types and amount of education provided by SLPs to family members or caregivers caring for individuals diagnosed with dementia. Committee members who are faculty of Eastern Kentucky University serving as professors in the Baccalaureate and Graduate Nursing Program, Occupational Science and Occupational Therapy Program and Communication Disorders Program reviewed the survey prior to publication. Following review, the questionnaire was published online via Qualtrics.

After opening the survey URL, a brief overview of the survey preceded the initial question (Appendix C). The overview explained the multiple choice format of the questionnaire. One key term, caregiver, was defined to differentiate the meanings of caregiver and family members, two terms used in the survey. Respondents were informed that by continuing to subsequent pages they provided their consent to participate. The survey was composed of 15 multiple choice questions and one descriptive question. The multiple-choice questions permitted intermittent descriptive texts. These descriptive texts were incorporated to encourage participants to expand on their responses. Participant demographic data were requested at the conclusion of the survey.

Data Analyses

Qualtrics online service was used to collect, safely store, and analyze the data. Descriptive statistics were used to analyze the data. Descriptive statistics organizes data into patterns that emerge during analysis (AECT, 2001). The responses from the descriptive texts on the survey were analyzed using a coding process. Coding is the process of organizing the data by bracketing and writing "codes" representing the data into the margins (Creswell, 2014). The descriptive responses were reviewed to identify general themes or topics (Ford, 2014). Identified topics were then compiled into a written list, clustered together by related topics and labeled a code. To increase inter-rater reliability of the codes, they were reviewed by two unbiased volunteers with no connection to the study (Phelan & Wren, 2005).

Central tendencies including mean, median and mode examined trends in the survey results. A correlational design was implemented to describe and measure the relationship of variables (Creswell, 2014). A Pearson Chi-Square test for Independence was used to analyze a frequency of a combination of two nominal variables (Aron, Coups &Aron). The test was used to determine an association between the participants' frequency of incorporating family members and caregivers. Data results were collapsed into smaller groups due to sparse data and in order to meet assumptions for Chi-Square test for independence. (Table 3.1)[1]. A Fisher's exact test was used to determine an association of perceived positive differences in individuals with dementia when family members or caregivers are incorporated into therapy. Again, the data were collapsed into smaller categories (Table 3.2). A second Fisher's exact test was conducted to compare reported positive differences in family members and caregivers when incorporated into therapy. Data were collapsed into 2 categories due to limited data (Table 3.3). A third Fisher's exact test was conducted to examine the relationship between reported amount of communication counseling provided family members and caregivers. Data were collapsed into 2 categories: 0 (Never; Very Little; Rarely) and 7

(Occasionally; Frequently; Always) (Table 3.4). To determine significance of the Fisher's exact tests, an absolute value greater than two was determined.

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[1] Refer to Appendices for tables

CHAPTER 4

RESULTS

This chapter presents results pertaining to incorporation of informal and formal caregivers into speech-language pathology services for persons with dementia. Speech-language pathologists (SLPs) provided their perspectives on the benefits and limitations for inclusion. Although not all questions from the questionnaire are presented, the questions contributing the information to this study's primary purposes are reported along with demographic data and anecdotal comments.

Participants and Demographics

Eighty-five individuals responded to the survey, but only 59 respondents attempted completion of the survey. One participant of the 59 began answering questions 1-3, but did not complete the entire survey. The participant was excluded from data analyses, but included in demographics. Another completed all survey questions but one (question 7). That participant was included in the data analyses.

All participants were certified and licensed speech-language pathologists. Participants ranged from 27-71 years of age (m=43.6). Respondents included 55 females and four males. Ninety-four percent of respondents reported having a master's degree and five percent a doctorate. The majority of respondents (n=53) identified employment in a skilled nursing facility or a hospital. Mean years of experience working with individuals with dementia was 14 years. Table 4.1 presents participant demographics.

Results of SLP Responses

SLPs' experience working with individuals with dementia. The majority (81%; *n* = 49) of participants reported having "a lot of experience" working with individuals with dementia. Sixteen percent (*n*=10) reported having "expert experience". One respondent reported having "frequent experience". Zero respondents reported having "no experience" and "minimal experience." Reported experience levels are presented in Table 4.2.

Percentage of individuals with dementia on the SLPs' current caseload. Thirty-six percent of participants (*n*=22) reported having "21-40%" of individuals with dementia on their current caseload. Twenty-one percent (*n*=13) reported having "41-60%" on their current caseload and twenty percent (*n*=12) "0-20%". Only 15% (*n*=4) reported having "61-80%" and 6% (*n*=4) "81-100" on their current caseload. Table 4.3 provides current caseload data.

Frequency of incorporating family members vs. caregivers in therapy sessions.

Family members. Three percent (*n*=2) of participants reported never (0%) incorporating family members into therapy. Eight percent (*n*=5) reported their incorporation frequency as "very little" (<20%) and 1% (*n*=1) "rarely" (<40%). Thirty-six percent (*n*=22) reported their frequency as "occasionally" (<60%). The majority of participants (38%; *n*=23) reported incorporating family members "most of the time" (<80%). Eleven percent (*n*=7) reported "always" (100%) doing so.

Caregivers. The majority (45%; *n*=27) of participants reported incorporating caregivers into therapy "frequently" (<80%). Twenty-five percent (*n*=15) reported "occasionally" (<60%). Eleven percent (*n*=7) reported "always" (100%) as their frequency. Ten percent (*n*=6) reported "rarely" (<40%). Only 3% (*n*=3) reported "very little" (<20%) and 1% (*n*=1) reported "never" (0%) incorporating caregivers. Table 4.4 outlines participants' frequency rates for incorporating caregivers into therapy with individuals with dementia.

A Pearson Chi Square test was conducted to compare if there was an observed association between incorporating family members and caregivers. Due to sparse responses, the survey response options for each question were placed into 3 groups: 0 (Never; Very Little; Rarely), 4 (Occasionally) and 7 (Frequently; Always). A 3x3 table was created to compare the two groups (Table 4. 5)). The association between incorporating family and caregivers was statistically significant (*p*=0.00).

Based on the results of the Pearson Chi-Square test, individual participants who reported that they either "Never; Very Litte; Rarely" incorporate family members into therapy reported the same for caregivers. Additionally, if individual participants selected either "Never; Very Little; Rarely" for family members, they would not select "Frequently; Always" for caregivers. Individual response of inclusion frequency were consistent between the two care provider groups.

Outcome in the individual with dementia when family members vs. caregivers are incorporated into direct therapy.

Family members. More often, participants (42%; *n*=25) reported observing "some difference" (51-75%) in individuals with dementia. Twenty-seven percent (*n*=16) reported observing "great difference" (76-89%) and 20% percent (*n*=12) "consistent difference" (>90%). Six percent (*n*=4) reported observing "very little" (1-25%) difference. Both 1% (*n*=1) of participants reported observing "no difference" (28-50%) and "never" (0%) a difference. Table 4.6 provides participant response data.

Thirty-two (54.24%) participants commented on types of positive differences observed in individuals with dementia when family members are incorporated into therapy. Responses were assigned a code based on general theme. Table 4.7 provides identified themes and assigned codes. Themes within assigned codes included: less stress, frustration and negative behavior. Also, participants reported that individuals with dementia showed carryover, generalization of skills, increased expressive language, participation and alertness (Table 4.7).

Caregivers. Similarly, more participants (39%; *n*=23) reported observing “some difference” (51-75%) in individuals with dementia when caregivers are incorporated into therapy. Twenty-nine percent (*n*=17) reported observing a “great difference” (76-89%) and seventeen percent (*n*=10) “consistent” (>90%) difference. Six percent (*n*=4) reported “no difference” (26-50%) and five percent (*n*=3) “very little” (1-25%). One percent (n=1) reported “never” (0%) observing a difference.

Twenty-eight (48.28%) participants chose to expand on types of positive differences observed in individuals with dementia when caregivers are incorporated into therapy. Responses were assigned a code based on its general theme. Themes identified included; decreased anxiety, frustration, falls and negative behaviors. Also, increased direction following, responses and carryover (Table 4.8).

A Fisher’s Exact Test was calculated to compare reported positive differences in individuals with dementia when family members or caregivers are incorporated into therapy. The test was used to identify if participants observe more of a positive difference in one group over the other. Only 57 participant responses were used to complete the test. One participant (P6) did not respond to the survey question (#7). Survey response options were collapsed into two categories: 0 (Never; Very Little Difference; No Difference) and 7 (Some Difference; Great Difference; Consistent Difference). A 2x2 table was created to compare the two groups (Table 4.9). The test concluded that there is an association in positive difference observed in the individual with dementia when family members or caregivers are included in therapy (*p*=0.00).

Outcomes in the family members and caregivers when incorporated into direct therapy.

Family members. Thirty-two percent (*n*=19) of participants reported observing a “great difference” (76-89%) in family members. Twenty-eight percent (*n*=17) reported observing “consistent difference” (>90%) and twenty-seven percent (*n*=16) “some difference” (51-75%). Five percent (*n*=3) observed “no difference” (26-50%). “Very little” (1-25%) difference was reported by 3% (*n*=2) of participants. Only 1% (*n*=1) reported “never” (0%) observing a difference. Table 4.10 provides participant response data.

Twenty-seven (45.76%) participants commented on their response of perceived difference. Responses were assigned a code based on its general theme. The following themes were identified: increased understanding, knowledge, confidence and patience. Additionally, decreased frustration, communication stress and anxiety were reported (Table 4.11).

Caregivers. More participants (33%; *n*=20) reported observing “some difference” (51-75%) in caregivers. Thirty-two percent (*n*=19) reported observing “great difference” (76-89%). Eighteen percent (*n*=11) reported observing “consistent difference” (>90%). Eight percent (*n*=5) reported “no difference” (26-50%). “Very little” (1-25%) difference was observed by 5% (*n*=3). One percent (*n*=1) reported “never” (0%) observing a difference (Table 4.10).

Twenty participants commented on positive differences observed. Responses were assigned a code based on its general theme. Frequent themes identified include the following: decreased frustration and stress, increased interaction, knowledge, empathy, patience and motivation (Table 4.12).

A Fisher’s Exact Test was calculated to compare reported positive differences in family members and caregivers when incorporated into therapy. The test was used to identify if participants observe more of a positive difference in one group than the other. Survey response options were collapsed into two categories: 0 (Never; Very Little Difference; No Difference) and 7 (Some Difference; Great Difference; Consistent Difference). A 2x2 table was created to compare the two groups (Table 4. 13). Results of a Fisher’s exact test, comparing the perceived differences in family members to caregivers when incorporated into therapy, showed that there is an association (p=0.00).

Fisher’s exact test data imply that there is an association between the two care provider groups. Participants who reported “Never; Very Little Difference; No Difference” observed in family members reported the same level of difference for caregivers. In addition, data imply that participants were less likely to report a low level of difference in family members and a high level of difference in caregivers.

Frequency of communication counseling provided to family members and caregivers.

Family members. Nearly half (42%) of participants reported providing counseling "frequently" (<80%) to family members. Thirty-two percent (*n*=19) of participants "always" (100%) provide counseling. "Occasionally" (<60%) providing counseling was reported by 16% (*n*=10) of participants. Eight percent (*n*=5) reported "rarely" (<40%) providing counseling. Zero percent (*n*=0) of participants reported "never" (0%) providing counseling and "very little" (<20%) counsel Table 4.14 provides participant response data.

Caregivers. More participants (38%; n=23) reported providing counseling "frequently" (<80%) to caregivers. Thirty-seven percent (*n*=22) reported that they "always" (100%) provide counseling. "Occasionally" (<60%) providing counseling was reported by 13% (*n*=8) of participants. Eight percent (*n*=5) reported "rarely" (<40%) providing counsel to caregivers. "Very little" (<20%) counseling was reported by 1% (*n*=1) and no respondents reported "never" (0%) providing counseling to caregivers. Table 4.14 provides participant response data.

A Fisher's Exact Test was calculated to examine the relationship between reported amount of communication counseling provided family members and caregivers. Family members and caregivers were compared to determine which group received more counsel. To conduct the test, survey response options were collapsed into two categories: 0 (Never; Very Little; Rarely) and 7 (Occasionally; Frequently; Always). A 2x2 table was created to compare the two groups. A significant association was found between family members and caregivers (*p*=0.00). Data imply that individual participants who rated that they "Never; Very Little; Rarely" provide communication training/counseling for family members provide the same level for caregivers (Table 4.15).

Types of communication training/information provided to family members and caregivers.

Family members. The majority (81%; *n*=51) of participants reported providing "explicit training with family members and individuals with dementia." Seventy-nine percent (*n*=47) reported "answering questions if family members approach with concerns." "Pamphlets or information from internet resources" was selected by 49% (*n*=29) participants. Three percent (*n*=2) participants reported providing "workshop training for family members." One percent (*n*=1) of the participants reported providing "video training." Zero participants (0%) reported that they "never give training or information." Table 4.16 provides participant response data.

Six participants commented on types of training/information provided. Responses were assigned a code based on its general theme. Themes identified include: books, model communication techniques, verbally mediate techniques in therapy and seek out family members on the phone. Table 4.17 provides participant descriptive response and its code.

Caregivers. The most (84%; *n*=50) participants reported providing "explicit training with caregiver(s) and individuals with dementia." Seventy-seven percent (*n*=46) reported "answering questions if caregiver(s) approach with concerns." Thirty-three percent (*n*=20) provide "interprofessional training" produced by them. Thirty-two percent (*n*=19) reported providing "pamphlets or information from internet resources." "Workshop training to caregivers" was provided by 10% (*n*=6). Six percent (*n*=4) reported "recommending interprofessional training not produced by the SLP." Zero percent (*n*=0) of participants reported "never providing training information" or "video training" (Table 4.16).

Five participants commented on types of training/information they provide to caregivers. Responses were assigned a code based on general themes. Trends in the codes include the following: in-service during orientation, modeling, on-the-spot education, providing examples, and seek out caregivers answering their questions. Table 4.18 provide participant responses and its code.

Factors that prohibit incorporation of family members and caregivers into therapy. Fifty-seven participants responded to survey questions 14 and 15. Two participants did not respond to either question but completed the remaining survey questions. Statistical analysis was completed on the 57 participant responses.

Family Members. Nearly all participants (96%; *n*=55) reported "lack of available family members" prohibited them from incorporating family members into therapy with individuals with dementia. Fifty-nine percent (*n*=34) reported "lack of willing family members" prohibited incorporation. "Time" was identified as a factor by 26% (*n*=5). Fifteen percent (*n*=9) reported "productivity requirements" and five percent (*n*=3) reported "reimbursement requirements". No respondents reported "lack of training "as a factor. Table 4.19 provides participant response data.

Seven participants commented on prohibiting factors. Responses were assigned a code based on its general theme. Code trends include the following: lack of availability, productivity levels and living arrangement. Table 4.20 provides participant responses and its code.

Caregivers. The majority (94%; *n*=54) of participants identified "availability of caregivers" as the top factor that prohibits them from incorporating caregivers into therapy. Twenty-six percent (*n*=15) reported that "time" was a factor. "Productivity rates" was identified by 15% (*n*=9) of participants. Ten percent (*n*=6) reported that "reimbursement restrictions" prohibited them from incorporating caregivers into therapy. "Lack of resources" was reported by 5% (*n*=3) of participants. Participants did not report "lack of training" as a factor (Table 4.19).

Eight participants commented on factors that prohibit them from incorporating caregivers into therapy with individuals with dementia. Responses were assigned a code based on its general theme. Trends in the assigned codes include the following: lack of willingness, availability, scheduling difficulty and productivity levels (Table 4.21).

Interest in knowing more about incorporating family members and caregivers into therapy.

Family Members. Nearly half (49%; *n*=29) of participants reported they have "some interest" in knowing more about how to incorporate family members. Forty percent (*n*=24) reported that they "definitely" want to know more. Six percent (*n*=4) reported "no interest." Three percent (*n*=2) reported that they have "very little" interest. Table 4.22 provides participant data.

Caregivers. "Some interest" in knowing more about how to incorporate caregivers into therapy with individuals with dementia was reported by the majority (54%; *n*=32) of participants. Thirty-seven percent (*n*=22) reported that they "definitely" have interest. "No interest" was reported by 6% (*n*=4); only one respondent indicated "very little interest" (Table 4.22).

CHAPTER 5

DISCUSSION

The current study examined SLPs' perspectives of incorporating family members and caregivers into therapy with individuals with dementia. In particular, the study examined the frequency of incorporating family members and caregivers into therapy, limitations to involving them, and strategies or approaches used to train them. Fifty-nine SLPs who work in a range of medical settings voluntarily responded to the survey. This chapter includes a discussion of results for each research question. Limitations and conclusions follow.

Response Rate

A 16-item survey was posted on three listservs and one public forum to reach SLP participants. Listservs chosen for the survey link were at a national level, reaching potentially thousands of SLP professionals. However, only 85 SLPs responded. Of the 85 respondents, 59 completed the survey in part or full and met inclusion criteria. While 59 participants would seem a low response rate for national exposure, the figure is acceptable for analyses in social science literature. The depressed response rate could be contributed to a lack of an incentive provided, time restraint, lack of interest in the topic, or limited experience treating individuals with dementia.

Do SLPs Incorporate Family Members and Caregivers into Therapy with Individuals with Dementia?

The majority of SLPs reported that they incorporate both family members and caregivers into therapy. Participants generally reported including family members (88%) and caregivers (83%) "occasionally" or "always". This suggests that SLPs are incorporating both groups into therapy more often than not. However, almost 11% of participants reported that they “rarely” to “never” incorporate family members into therapy. Sixteen percent “rarely” to “never” incorporate caregivers. Data imply that participants are not explicitly excluding one care provider more than the other – there is generally an incorporation of both groups. However, comparing the two percentages, participants do not include caregivers as often as family members. This suggests that there may be factors prohibiting SLPs from incorporating caregivers more than family members.

Research has suggested that incorporating either group into therapy is beneficial for the caregiver, family members, and individual with dementia (Neely et al., 2009; McGilton et al., 2009). Results indicate that SLPs do incorporate them regularly. Practitioners appear to recognize the value of family and caregiver participation despite factors that may prohibit incorporation.

Do SLPs Report Providing Communication Training and/or Information to Family Members or Caregivers of Individuals with Dementia?

Participants generally reported that they do provide communication training/counseling to family members (91%) and caregivers (89%) “occasionally” or “always”. However, 8% of participants reported that they “rarely” to “never” provide communication training/counsel to family members. Ten percent reported that they “rarely” to “never” provide communication training/counsel to caregivers. This suggests that participants appear to be providing communication training/counseling to family members more than caregivers. It also implies that there are factors prohibiting SLPs from providing communication training/counseling equally to both groups. Regardless, the level of communication/counseling provided is consistent and at a relatively high level. This suggests that participants view family members and caregivers with equal importance. They understand that the person spending the most time with the individual with dementia should be the one receiving communication training/counseling.

The majority of participants (88%) “occasionally” to “always” incorporate family members into therapy. However, this percentage is slightly lower compared to providing training/counseling to family members (91%). Similarly, 89% percent of participants reported “occasionally” to “always” providing training/counsel to caregivers, but 83% “occasionally” to “always” incorporate caregivers. Again, the percentage of participants providing communication training is slightly higher than the percentage of actual inclusion in therapy. Given these data, it may be that the majority of training/counseling is perceived as being outside of therapy.

Watson and colleagues (2013) identified that individualized education and training targets specific communication enhancement strategies and improves multiple modalities in both individuals with dementia and their caregiver. It reportedly reduces caregiver burden, decreases depersonalization, and increases quality of life (QoL) for patients with dementia. Eggenberger and colleagues (2013) found similar results with increased QoL as well as enhanced positive behaviors. Others suggest communication training should be a three-pronged approach: educational training, practice and support (McGilton et al., 2009). The training should include opportunities to practice techniques and strategies with the individual with dementia (McEvoy & Plant, 2014). Results from the current study suggest participants are providing training/counseling but may not be providing equal opportunities for practice and feedback with therapy inclusion.

Results also suggest participants are consistently providing communication training/counseling to both family members and caregivers. The SLPs acknowledge that the two groups are vital components in the therapy process of individuals with dementia. Results confirm that practitioners recognize the value communication training/counseling provide to individuals who communicate regularly with the individual with dementia.

What Perspectives Do Speech-Language Pathologists Report with Regard to Incorporating Family Members and/or Caregivers into Therapy with Individuals with Dementia?

Most participants (47%) reported observing a “great” to “consistent” difference in individuals with dementia when family members are incorporated into therapy. Participants reported more of a positive difference in individuals with dementia than not. This finding supports previous research. In particular, collaborative therapy has been shown to improve episodic memory and interaction in individuals with dementia (Neely et al., 2009). In the present study, participants reported the following behavior changes in individuals with dementia secondary to family member involvement: improved social interaction and communication attempts, improved memory, improved use of strategies, increased carryover of skills, and decreased agitation and negative behaviors. One participant reported observing “decreased falls,“ suggesting a safety benefit for inclusion.

Similarly, nearly half (46%) of participants reported observing a “great” to “consistent” difference in individuals with dementia when caregivers are incorporated into therapy. Increased carryover of skills, increased attempts to communicate, and reduced negative behaviors mirror the positive behavioral changes reported secondary to family member participation. These results provide further support for the collaboration results of Neely and colleagues (2009).

As a whole, the majority of participants observed a positive difference in individuals with dementia when either care provider group was incorporated into therapy. Results further imply that if a participant reported that they observed “Never; Very Little Difference; No Difference” when family members were incorporated, the same level of difference was reported with incorporating caregivers. This finding suggests that there is not a clear group that individual participants believe generate more positivity in individuals with dementia.

Perhaps having a familiar presence in the therapy session such as a family member or caregiver eases stress levels in individuals with dementia. High levels of stress with communication breakdowns may increase agitation in individuals with dementia (Barnes, 2012; Enmarker et al., 2010; Vasse et al., 2010). Including someone that an individual with dementia speaks to regularly may promote more communication attempts and decrease stress levels. It is unrealistic for SLPs to assume that an individual with dementia will not initially feel uncomfortable or hesitant to engage in therapy without some level of familiarity or relationship present.

Comparing the percentages of the two groups, results suggest that participants observe less of a positive difference in caregivers than in family members when incorporated into therapy. This may be due to lack of communication training, lack of inclusion in therapy, decreased time to practice communication strategies, or unwillingness to use given communication strategies. However, some participants (16%) “rarely” to “never” incorporate caregivers into therapy. Participant responses suggested that time (or lack of it) was a factor for not including caregivers. One participant stated, “Caregivers in facilities have less one on one time with pts (patients) typically ... sharing their time with multiple pts on caseload so results are slightly less positive.” Another participant stated that, “They (caregivers) usually don't have the luxury of spending time in therapy sessions - recommendations are made after the fact.” Despite observable positive differences when caregivers are incorporated into therapy, there appears to be a lack of opportunity for inclusion.

Specifically, 60% of participants reported that they observed a “great” to “consistent” level of positivity in family members when incorporated into therapy with individuals with dementia. Of the 60%, 32% reported observing a “great difference.” Decreased frustration and increased empathy were the most frequently reported characteristics of the positivity. An increase in knowledge or understanding of dementia was also reported. Previous research has suggested that family members are not receiving the information they need about dementia at the time of diagnosis (Balkanska, 2012; Georges et al., 2008). Results of the present study suggest that incorporating family members into therapy naturally provides the necessary information family members are seeking to better understand dementia and its impact on their loved one.

Half of participants reported they observed a “great” to “consistent” level of positivity difference in caregivers when incorporated into therapy with individuals with dementia. Participants reported that caregivers demonstrate an increase in positive communication and empathy or kindness towards the persons with dementia. These results support previous research that found decreased depersonalization and increased empathy in caregivers after communication training (Paasalacqua &Harwood, 2012; Zientz, Backley & Chapman, 2007).

However, participants also expressed that caregivers can be unreceptive to communication training. One participant stated that, “At times it seems that for the caregiver to take a few moments - to learn how to interact or use more effective, specific, techniques - results in increased anxiety and impatience in the caregiver, i.e., ‘now I'll have more work to do, more things to remember to do...” Another participant stated, “Although I feel the caregivers would benefit (as would the patient), many of them feel they already know what to do and are frequently not receptive to recommendations (in my experience).” Paasalacqua and Harwood (2012) found that caregiver participants appreciated “to-the-point” type of training. These comments support the acknowledgement that time constraints and workload are perceived to be an interfering factor for participation and training. It would seem that time is not just a factor for the SLPs, but for the caregivers as well. Coordinating a joint time that permits meaningful and comprehensible strategies appears challenging in today’s medical settings.

What Limitations Do Speech-Language Pathologists Report Involving Family Members and/or Caregivers into Therapy?

Limitations to involving family and caregivers into therapy included availability and time. The primary factor reported for prohibiting participants from incorporating both family members and caregivers into therapy was availability. One participant stated, “Often family members are from out of town, or all do not come in for training. It is more of catch-as catch-can.” Participants reported that unwilling family members are also a limitation. Unwillingness of a family member may be linked to several factors including lack of information about dementia or burnout. This finding supports the need for providing communication training and its potential for reducing caregiver burden (Watson et al., 2013).

Time to include both family members and caregivers was also the second leading factor. Interestingly, it was ranked by the same number of participants for both groups. It is worthy to note that the survey did not provide a definition of “time.” It is unclear whether it was viewed as the time frame of a session or the length of a treatment plan. Time may also have been interpreted in relation to productivity levels at the facilities. For example, one participant stated, “Productivity rates are out of the roof. Mine is 95%.” Whether time is related to productivity or other parameters, it an issue for training family members and caregiver groups.

Lack of SLP training was not selected by any participant as a factor influencing training to families or caregivers. This result is both encouraging and noteworthy. SLPs feel equipped to provide crucial training to individuals with dementia and their caregivers. Providing education and training is a part of a SLPs scope of practice (Watson et al., 2013). Results indicate that SLPs appear to adapt training/counseling into their practice with confidence.

If Family Members and Caregivers are Incorporated into Therapy, What Methods do Speech-Language Pathologists Use to Train Them?

The majority of participants reported the primary method used was “explicit training with family members and Individuals with dementia”. Answering questions prompted by family members was ranked second. Interestingly, explicit training and answering questions were also the highest ranked methods for caregivers. A third ranked method used with family members was providing pamphlets or information from internet sources.

Results support recommendations made by Lubinski (2003). Family members and caregivers accept and respond to explicit training that provides information on how to problem solve situations they might encounter. Lubinski also stated that family members and caregivers do not want a list of “Do’s or Don’ts.” Participants ranked providing pamphlets and information from internet source as a common method. It is unclear whether their sources might be considered in the “Do’s or Don’ts” category. Attention to the type of pamphlets and information being given to family members and caregivers is important to consider. Information that is qualitative and descriptive may be preferable to more prescriptive information.

Workshops were ranked lower than other methods for both groups. Due to reported insufficiency of available family members, caregivers, and time, this result was not surprising. Video training was ranked the lowest for training both family members and caregivers. This result is not surprising considering participants indicated that availability of family members and caregivers was a factor prohibiting them from providing communication training. A video training may be a more time intense method. It would require a specific scheduled period in which to present the information and a commitment for participants to remain throughout. However, a video training may be a flexible method that can accommodate the care provider’s schedule. For instance, a video could be taken home by the family member to watch independently and return with questions. It may also be implemented during an in-service or orientation for caregivers.

Interprofessional training to caregivers provided by the SLP was ranked third by participants. One participant reported that training occurs during “in-servicing at orientation.” Providing training during staff orientations may be a viable option for SLPs. Orientations are typically required by employers and increasingly includes specifics to service provision from other professionals. Embedding the training in orientation process may make the availability of caregivers during that time a decreased prohibition. Interprofessional training for caregivers not provided by a SLP was not viewed as desirable. This result may suggest that SLPs think it inappropriate or difficult to find an individual with sufficient expertise to train in the area of communication with individuals with dementia.

Each participant reported providing at least one method of training or information sharing to both family members and caregivers. This finding further confirms that SLPs are providing communication training in cognitive service provision (Purves & Phinney, 2013). It clearly is a valued component to include in their practice (Watson et al., 2013).

Interest in learning more about incorporating family members and caregivers into therapy was reported. Surprisingly, some participants indicated that they have “very little” or “no interest” in doing so. It is unclear why these participants have minimal interest, but is contrary to research indicating the positive outcomes for individuals with dementia (Eggenberger et al., 2013; Watson et al., 2013; Zientz, Backley & Chapman, 2007). Perhaps, they believe they have sufficient expertise and experience for incorporating both groups. However, most participants who reported that they have “very little” or “no interest” indicated that they have lower percentages of individuals with dementia on their caseloads. This may suggest that until there is a predominant need, the practitioners cannot or do not want to expend time and resources in areas without immediate application and benefit.

Strengths and Limitations

The present research explores the positive effect of incorporating the caregiver into therapy for the individual with dementia, but did not distinguish the positive effects by provider groups. A strength of the current study is that it expands the research examining the perceived outcomes of the family member, caregiver, and individual with dementia when incorporated into therapy or provided communication training. Results support the need and benefits for incorporating family members and caregivers into therapy with individuals with dementia. Positive outcomes were observed by SLPs when incorporated into therapy. Involving family members and caregivers may reduce caregiver burden and increase generalization of skills in individuals with dementia.

As with many studies, high participant response rate is never guaranteed. The response rate of this study limits the generalization of results. It is unknown how many participants viewed the link to the survey and chose to not complete it. It is unknown why 30 individuals did not follow through. The inclusion criteria would have excluded SLPs with less than one-year experience with individuals with dementia from completing the survey. These individuals may have contributed valuable insights. However, it was determined that one year of experience would have prevented those practitioners who may have been acclimating to their particular setting from skewing the results. At the same time, one year may not be a sufficient parameter to assure that practitioners could develop the necessary relationships with caregivers or family members to provide training/counseling on dementia. The primary investigator also recognizes that the one year inclusion criteria did not clarify whether that was full-time or part-time service provision. It is not unreasonable to believe that part-time practitioners at any given medical setting would be at a disadvantage for developing a training/counseling process for family members and caregivers.

Several terms in the survey were not explicitly defined, leaving them open for interpretation by the participant. The term “time” for example, may represent several concepts. It could have been interpreted as length of session or therapy program, time in the day, the care provider’s flexibility of time, or time within the disease’s stage. Another term that was not explicitly defined was “counseling.” This term could be interpreted as providing emotional support or factorial information. Lacking clear definitions for terms such as these, may not allow the participant to clearly express their experience and perspective.

The term “caregiver” was defined in the survey introduction. However, based on multiple participant responses, it was clear that they did not understand the term. One participant commented “I'm not sure I'm understanding the delineation between caregiver and family member- does this mean paid caregivers?” Another participant commented on their confusion regarding the difference between family members and caregivers stating, “seems redundant to prior questions; I do not perceive the difference in this question.” Based on the comments, some confusion limited participants’ ability to express their true experience and perspective.

A survey method of data collection may also limit the depth of participant response. Question response options were selected by the primary investigator to guide participant thinking. However, each response option provided could not possibly represent all ideas. Consequently, the range of potential findings was limited. Descriptive responses were available for participants to expand on their answer, but not utilized by all. The present research topic prompted a collection of qualitative data. Statistical analyses are limited with such studies. Therefore, the current study attempted to present qualitative information in a quantitative manner. Few statistical tests could be conducted on the data which limited additional findings.

Conclusion

Data from the present study indicate that incorporating family members and caregivers into intervention with individuals with dementia is not an uncommon practice. SLPs understand that incorporating the two groups is vital. More SLPs than not, understand that language breakdowns will occur as the disease continues into later stages. However, despite lack of time and availability of family members and caregivers, SLPs are making an effortful attempt to provide their expert knowledge to the two groups.

Productivity levels were reported by the same number of SLPs (*n*=9) as being a prohibiting factor for not including family members or caregivers into therapy. According to ASHA (2015), 59.6% (*n*=916) of 1, 537 SLPs in a medical employment setting have productivity requirements set by their employer. Additionally, 87.5% (*n*=723) of 827 SLPs reported that they have a 75th percentile productivity requirement (ASHA, 2015). Unfortunately, due to employers' demands and decreasing rates by reimbursement sources, productivity levels may become an increasing factor preventing incorporation of family members and caregivers into therapy. Research is needed to assure equity of care throughout the disease process regardless of productivity levels.

Availability of family members and caregivers was also reported as a top prohibiting factor of incorporating the two groups into therapy. With a rise in technology, communication from a distance is simpler and easier. Given that, SLPs may be utilizing technology more. With an increasing use of telepractice and internet modalities such as Skype and Facetime, telepractice communication with caregivers may permit more flexibility in availability and access. In the present study, a large majority of SLPs already employ technology as a means of providing communication training. As a younger cohort of SLPs already steadily immersed in the use of technology join the workforce, the percentage of SLPs using technology as a way to provide communication training/counseling may further increase.

Implications

The current study found that there are positive outcomes in individuals with dementia, family members, and caregivers when incorporated into therapy. However, previous research has found that care providers do not consistently receive information on how to access assistance from a SLP (Eggengerger et al., 2013; Georges et al., 2008; Lubinski, 2003; Watson et al., 2013). An effort should be made by SLPs to inform primary practitioners of their expertise in providing cognitive therapy. Establishing a collaborative relationship may increase the percentage of care providers receiving valuable information. These may result in decreased caregiver burden and increased QoL for individuals with dementia.

Future Research

Future research could examine more specifically how communication training effects the care provider, SLP, and individual with dementia. Each person associated with the disease has useful information and meaningful perspectives that could reduce burdens and improve quality engagement day in and day out. Determining delivery in relation to disease progression may inform practitioners on the most efficient and effective time in which to incorporate family members or caregivers to gain the most positive outcomes. This would better inform SLPs as to when their time and resources for communication training would be most helpful. It might also decrease the negative influence of time, allowing better planning for time allocations.

Expanding the survey administration to not only the SLP but both care provider groups may increase understanding of each group's perspective. The family member and caregiver hold valuable information and experiences. Therefore, capturing their thoughts regarding communication training/counseling and comparing it to the SLPs' perspectives may generate new light on the topic.

In addition, knowing which method of training is perceived by the care provider to be most helpful can aid SLPs in their practice. One method may be viewed as beneficial by the SLP but not the care provider. Results of the present study suggest that most caregivers feel burdened by communication training because they see it as another task to complete. Further research could determine if there is a method that benefits caregivers without adding to their workload. Perhaps, key to examine is whether an important component to training is changing perceptions that communication efforts add to their caretaking efforts rather than ease them.

Given the anecdotal evidence from the current study, future research could explore the effects of communication in reducing falls. The results of the research may make SLPs more valued in facilities where fall rates are monitored, such as rehabilitation facilities and hospitals. Conversely, if demonstrated to reduce falls, subsequent training with family members could reduce nursing home or assisted facility placements and extend independent living. Overall, the research could increase wellness and quality of life for the individual with dementia, reduce caregiver burden, and promote a safer environment in facilities or at home.

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APPENDICES

Appendix A:
Recruitment Letter

Recruitment Letter

Dear Potential Participant,

I am a graduate student in the Communication Disorders Program at Eastern Kentucky University and I would appreciate your assistance. For my master's thesis, I am interested how speech-language pathologists incorporate family and caregivers in direct service provision for individuals with dementia. The frequency of incorporating caregivers and families into treatment, limitations to involving them, and strategies or approaches used to train them will be examined. Your participation and input as a respected professional would be greatly appreciated.

To participate in the survey, you must be a licensed and ASHA certified speech-language pathologist who has worked in a skilled nursing facility, private practice, nursing home facility, home health or other medical setting within the past year. Your participation in this survey is entirely voluntary. You are not required to provide any personally identifiable information. At no point will your contact information be linked to your survey responses. All data will be reported in aggregate.

Please click link below to begin the survey:

https://qtrial2016q2.az1.qualtrics.com/SE/?SID=SV_eW0gvyGhJF3tiOF

ngIf: shouldUseShortenedSurveyUrls

Should you have any question about the research or your participation, please contact me at Jocelyn_hartley2@mymail.eku.edu or my thesis mentor, Dr. Tamara Cranfill, CCC/SLP, at Tamara.Cranfill@eku.edu.

Jocelyn Hartley

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Appendix B:
Survey Questionnaire

Survey Questionnaire

Please answer the following questions by selecting the box that BEST describes your response.

1.How would you rate your experience working with individuals with dementia?

- ■ No experience (I have never worked with a client diagnosed with dementia.
- ■ Minimal experience (I have worked with less than 15 clients diagnosed with dementia,)
- ■ Frequent experience (I have worked with 16-25 clients diagnosed with dementia.)
- ■ A lot of experience (I have worked with more than 25 clients diagnosed with dementia.)
- ■ Expert experience (The majority of my experience is with clients with dementia.)

2.What percentage of individuals with dementia are on your current caseload?

- ■ 0-20%
- ■ 21-40%
- ■ 41-60%
- ■ 61-80%
- ■ 81-100%

3.How often do you incorporate family members into your therapy session with individuals with dementia?

- ■ 0-Never (0%)
- ■ 1-Very Little (<20%)
- ■ 2-Rarely (<40%)
- ■ 3-Occassionally (<60%)
- ■ 4-Most of the Time (<80%)
- ■ 5-Always (100%)

4.How often do you incorporate caregiver(s) into your therapy session with individuals with dementia?

- ■ 0-Never (0%)
- ■ 1-Very Little (<20%)
- ■ 2-Rarely (<40%)
- ■ 3-Occassionally (<60%)
- ■ 4-Frequently (<80%)
- ■ 5-Always (100%)

5.Do you see a positive difference in the individual with dementia when family members are incorporated into direct therapy? A positive difference is defined as an observed or objective increase in communication, cognitive and/or language skill. Examples include but are not limited to improved communication ability, increased socialization, increased memory recall and/or decreased problematic behavior.

- ■ 0-Never (0%)
- ■ 1-Very Little (1-25%)
- ■ 2-No Difference (26%-50%)
- ■ 3-Some Difference (51%-75%)
- ■ 4-Great Difference (76%-89%)
- ■ 5-Consistent Difference (>90%)
- ■ Please describe type(s) of positive difference: ____

6. Do you see a positive difference in the individual with dementia when caregivers are incorporated into direct therapy?

- ■ 0-Never (0%)
- ■ 1-Very Little (1-25%)
- ■ 2-No Difference (26%-50%)
- ■ 3-Some Difference (51%-75%)
- ■ 4-Great Difference (76%-89%)

- 5-Consistent Difference (>90%)
- Please describe type(s) of positive difference:
  ____
  ____
  ____

7. Do you see a positive difference in the family members when incorporated into direct therapy? Positive difference is defined as an observed increase in communication, knowledge, attitude and/or participation with the individual with dementia.

- 0-Never (0%)
- 1-Very Little (1-25%)
- 2-No Difference (26%-50%)
- 3-Some Difference (51%-75%)
- 4-Great Difference (76%-89%)
- 5-Consistent Difference (>90%)
- Please describe type(s) of positive difference:
  ____
  ____
  ____

8. Do you see a positive difference? in the caregiver(s) when incorporated into direct therapy?

- 0-Never (0%)
- 1-Very Little (1-25%)
- 2-No Difference (26%-50%)
- 3-Some Difference (51%-75%)
- 4-Great Difference (76%-89%)
- 5-Consistent Difference (>90%)
- Please describe type(s) of positive difference:
  ____
  ____
  ____

9. How often do you counsel family members about the communication effects? Examples of communication effects may include but are not limited to the lack of communication ability, effects of memory and/or word recall, adherence to conversation rules (turn-taking) and/or decreased auditory comprehension.

- 0-Never (0%)
- 1-Very Little (<20%)
- 2-Rarely (<40%)
- 3-Occassionally (<60%)
- 4-Frequently (<80%)
- 5-Always (100%)

10.How often do you counsel caregiver(s) about the communication effects dementia will have on the individual with dementia?

- 0-Never (0%)
- 1-Very Little (<20%)
- 2-Rarely (<40%)
- 3-Occassionally (<60%)
- 4-Frequently (<80%)
- 5-Always (100%)

11.How do you provide communication training/information to family members? (Check all that apply)

- Never give training or information
- Video training
- Pamphlets or information from internet resources
- Explicit training with family members and individual with dementia
- Workshop training provided for family members
- Answer questions if family members approach with concern
- Other (Please explain)____

12.How do you provide communication training/information to caregiver(s)? (Check all that apply)

- Never give training or information
- Video training
- Pamphlets or information from internet resources
- Explicit training with caregiver(s) and individual with dementia
- Workshop training provided for caregiver(s)
- Answer questions if caregiver(s) approach with concern
- Recommend interprofessional training (not provided by you
- Provide interprofessional training (by you)
- Other (Please explain)____

13. Which of the following, if any, prohibits you from incorporating family members into therapy with individuals with dementia? (Check all that apply)

- Time
- Lack of training
- Lack of available family members
- Lack of willing family members
- Lack of resources
- Reimbursement restrictions
- Productivity requirements
- Other (Please explain):____

14.Which of the following, if any, prohibits you from incorporating caregivers into therapy with individuals with dementia? (Check all that apply)

- Time
- Lack of training
- Availability of caregivers
- Lack of resources
- Reimbursement restrictions

- Productivity requirements
- Other (Please explain):____

15.Do you wish you knew more about incorporating family members into therapy with individuals with dementia?

- 0-No
- 1-Very Little interest
- 2-Some Interest
- 4-Definitely

16.Do you wish you knew more about incorporating caregiver(s) into therapy with individuals with dementia?

- 0-No
- 1-Very Little interest
- 2-Some Interest
- 4-Definitely

17. Other comments or clarifications with regard to the research topic:____
____

Demographic Information:

Age:________________ Years

Gender: Male Female

Years of Experience with Individuals with Dementia:

____

Employment:

- Full Time
- Part Time
- Contracted by Agency

Types of Current Employment (Check all that apply)

- Skilled Nursing Facility
- Home Health
- Private Practice
- Hospital
- Rehabilitation Facility
- Outpatient Clinic

Highest Degree Earned:

- Master's Degree
- Doctorate

Appendix C:
Introduction to Survey Questionnaire

Introduction to Survey Questionnaire

The following questionnaire will examine your experience of incorporating families and caregivers into direct therapy with individuals with dementia. Caregivers are defined as unpaid or paid individuals, not related to client/patient, who aid individuals with dementia with activities of daily living (e.g., paraprofessionals or nurses). The following survey consists of 16 multiple choice questions. Please select the box that best fits your response.

The answers you provide will be kept anonymous. No identifying information will be published or presented. You may choose to discontinue the survey at any time with no consequences. By proceeding to the next page, you will be providing consent to use your answers for the purpose of the research study.

Appendix D:
Tables

Table 3.1

Pearson Chi-Square Test Data Collapse: Frequency Options of Incorporating Family Members and Caregivers into Therapy

Collapsed Response Groups:
0 (Never; Very Little; Rarely)
4 (Occasionally)
7 (Frequently; Always)

Table 3.2

Fisher's Exact Test Data Collapse: Perceived Outcome Options in Individuals with Dementia when Family Members or Caregivers are Incorporated into Therapy

Collapsed Response Groups:
0 (Never; Very Little Difference; No Difference)
7 (Some Difference; Great Difference; Consistent Difference)

Table 3.3

Fisher's Exact Test Data Collapse: Perceived Outcome Options in Family Members or Caregivers When Incorporated into Therapy

Collapsed Response Groups:
0 (Never; Very Little Difference; No Difference)
7 (Some Difference; Great Difference; Consistent Difference)

Table 3.4

Fisher's Exact Data Collapse: Frequency Options for Providing Communication Counseling to Family Members and Caregivers

Collapsed Response Groups:
0 (Never; Very Little; Rarely)
7 (Occasionally; Frequently; Always)

Table 4.1

Demographic Characteristics for Participants (N = 59)

Demographic Characteristics	Percentage	(*n*)
Gender		
Male	6.78	4
Female	93.22	55
Education Level		
Master’s	94.92	56
Doctorate	5.08	3
Employment Setting		
Skilled Nursing Facility	47.46	28
Home Health	23.73	14
Private Practice	13.56	8
Hospital	42.37	25
Rehabilitation Facility	40.68	24
Outpatient Setting	32.20	19
Employment Type		
Part Time	14.29	8
Full Time	78.57	44
Contracted by Agency	7.14	4
Years of experience	*m*=14.61	
Age, mean years	*m*=43	

Table 4.2

Experience Working with Individuals with Dementia

Experience Level	Percentage	(*n*)
No Experience	0.00	0
Minimal Experience	0.00	0
Frequent Experience	1.67	1
A Lot of Experience	81.35	48
Expert Experience	16.67	10

Table 4.3

Percentage of Individuals with Dementia on Current Caseload

Percentage Range	Percentage	(*n*)
0-20%	18.64	11
21-40%	36.67	22
41-60%	21.67	13
61-80%	15.00	9
81-100%	6.67	4

Table 4.4

Frequency SLPs Incorporated Family Members and Caregivers into Therapy with Individuals with Dementia

Percentage of Frequency	Percentage	(*n*)
Family Members		
Never (0%)	1.66	1
Very Little (<20%)	8.33	5
Rarely (<40%)	1.67	1
Occasionally (<60%)	36.67	22
Most of the Time (<80%)	38.33	23
Always (100%)	11.67	7
Caregivers		
Never (0%)	1.69	1
Very Little (<20%)	5.08	3
Rarely (<40%)	10.17	6
Occasionally (<60%)	25.42	15
Most of the Time (<80%)	45.76	27
Always (100%)	11.86	7

Table 4.5

Pearson Chi-Square Test: Comparison of Incorporated Family Members and Caregivers into Therapy with Individuals with Dementia

	0	4	7	All
0	5	2	0	7
	1.186	1.780	4.034	
	3.5011	0.1652	-2.0085	
	12.2579	0.0273	4.0339	
4	4	5	13	22
	3.729	5.593	12.678	
	0.1404	-0.2508	0.0904	
	0.0197	0.0629	0.0082	
7	1	8	21	30
	5.085	7.627	17.288	
	-1.8115	0.1350	0.8927	
	3.2814	0.0182	0.7970	
All	10	15	14	59

Fisher's exact test: p = 0.00

Table 4.6

Observed Positive Difference in Individuals with Dementia when Family Members and Caregivers Were Incorporated into Therapy

Level of Difference	Percentage	(*n*)
Family Members		
Never (0%)	1.69	1
Very Little (1-25%)	6.78	4
No Difference (26-50%)	1.69	1
Some Difference (51-75%)	42.37	25
Great Difference (76-89%)	27.12	16
Consistent Difference (>90%)	20.34	12
Caregivers		
Never (0%)	1.72	1
Very Little (1-25%)	5.17	3
No Difference (26-50%)	6.90	4
Some Difference (51-75%)	39.66	23
Great Difference (76-89%)	29.31	17
Consistent Difference (>90%)	17.24	10

Table 4.7

Anecdotal Comments and Coded Themes Identified in Response Regarding Outcomes Observed in Individuals with Dementia When Family Members are Incorporated into Therapy

Participant	Response	Themes
P3	More contentment of family with care provision; more communication attempts during visits	>Interaction
P3	More contentment of family with care provision; more communication attempts during visits	>Interaction
P4	Decreased inappropriate behaviors; "happier" (only my perception); improvement with following directions; decrease in falls	< Negative behaviors <Falls > Direction following
P5	Patients are generally more interactive and responsive in the presence of family/friends.	>Interaction >Response
P9	Improved social interactions, less agitation	> interaction <agitation
P10	When family participate in therapy along with their loved one who has dementia, I have seen better support of the person with dementia and follow through on provided strategies.	>Carryover
P13	Response to familiar voices	> Response
P14	Improved socialization with increased attempts to engage in communication, increased orientation, pt's overall QOL	>Interaction >Quality of Life
P15	Greater carryover of strategies	>Carryover
P20	More responsive	> Response
P23	Less C/O negative behaviors	<Negative behaviors
P25	Increased carryover, improved memory, improved use of strategies, less problematic behavior, more appropriate interactions with others	>Carryover <Negative behaviors > Strategy use
P27	Reduced communicative stress (on the part of both communicative partners: the partner with dementia and the caregiver partner)	< Communication stress

Table 4.7 (continued)

Participant	Response	Themes
P28	Better participation and better carryover	>Participation >Carryover
P31	Carryover with skills addressed of decreased problematic behavior and better communication skills.	Generalization < Negative behaviors > Communication
P33	Family members learn how to decrease unwanted behaviors and support the patient in recalling ADLs, swallow strategies, etc.	<Negative behavior >Support
P37	Improved socialization as well as improved recall of biographical information/family members and friends.	>Social >Biographical memory recall
P38	Increased communication interaction. Increased motivation to communicate. Increased enjoyment of communicating. Increased willingness to attempt communicating with others.	>Interaction >Enjoyment of communication >Participation
P40	Limited ability to observe due to limited therapy sessions approved by insurance.	N/A
P41	Greater participation by the person with dementia: more alert, more receptive, more expressive, more on task / on topic, more willing to interact and participate with either/both family and a long-term, familiar caregiver. Improved responses to attend, to communicate, to eat/drink, to attempt self-care ADL's, calming effect, etc. if family has lived with or close by and frequently/routinely interacts with the person with dementia.	>Participation >Alertness >Expressive language >Response
P42	I see improved carryover of skills and strategies; improved interactions between pt and caregiver; increased autonomy	>Carryover >Automaticity >Interaction

Table 4.7 (continued)

Participant	Response	Themes
P45	Reduction in stress in family member, which "spreads" (sometimes) to enhanced function in person with dementia.	<Stress
P46	Less frustration, agitation	<Frustration
P47	Improved response to cuing Improved targeting of meaningful skills	>Response
P50	More alert. Often a family member is the only one that can successfully feed the patient. Knowledge of communication strategies is power for families. When they incorporate them, they usually see positives right away.	>Alert >Strategies
P72	Use of recommended communication strategies	> Communication Strategies
P75	The majority of my experience has been in a skilled nursing facility. Unfortunately, I have never included a caregiver or family member in therapy sessions with individuals with dementia as they are rarely, if ever, present while therapy is taking place.	N/A
P76	Maintain regular diets longer and decrease Fall risk	Diet Maintenance < Falls
P78	Decreased behavioral difficulties, decreased confusion, increased participation/buy-in to therapy	< Negative behavior
P79	Increased consistency in the use of compensatory strategies at home. Improved household interaction because family members have been educated re: how to interact. These are only a few examples.	>Consistency >Interactions
P80	Increased family/caregiver understanding of dementia; ability to model appropriate communication strategies; training of family/caregiver to implement compensatory strategies	>Understanding
P82	Increased expressive language	>Expressive language
P87	Essential for carryover and generalization Visuals development Real life, individualized targets	Carryover & Generalization

Table 4.8

Participant Anecdotal Comments and Coded Themes Identifies on Positive Outcomes in Individuals with Dementia when Caregivers Are Incorporated into Therapy

Participant	Response	Themes
P3	Fewer behavioral outbursts	<Negative behavior
P4	Same as response to previous question	< Negative behaviors <Falls > Direction following
P9	Less agitation	<Negative behavior
P10	When caregivers participate in therapy along with their loved one who has dementia, I have seen better support of the person with dementia and follow through on provided strategies.	>Carryover
P13	At times can follow more directions	>Direction following
P14	Same as above although caregiver's in facilities have less 1 on 1 time with pts typically ... sharing their time with multiple pts on caseload so results are slightly less positive.	>Interaction > Quality of Life
P15	Greater carryover of strategies	>Carryover
P25	Same as above	>Carryover <Negative behavior
P27	Reduced communicative stress (on the part of both communicative partners: the partner with dementia and the caregiver partner)	<Communication stress
P28	Better carryover and better understanding/ empathy of the caregiver	>Carryover
P31	Carryover with skills addressed of decreased problematic behavior and better communication skills.	<Negative behavior >Carryover >Communication
P33	Although, if you mean nurses, nurses' aides as caregivers (rather than family caregivers), they usually don't have the luxury of spending time in therapy sessions - recommendations are made after the fact.	N/A

Table 4.8 (continued)

Participant	Response	Themes
P35	Patient seem to react more positively with caregivers during treatment. Patient tend to follow commands from caregivers better than from family.	>Direction following
P37	Increased socialization and better communication of wants and needs.	>Communication
P38	Increased willingness to attempt to communicate. Increased ability to communicate. Increased enjoyment of communicating.	>Communication >Communication pleasure
P40	Ease of communication	>Communication
P41	The longer duration/time of the relationship and the more positive the relationship with the caregiver, then the greater the positive influence of the caregiver on the person with dementia: to attend, to communicate, to eat/drink, to attempt self-care ADL's, calming effect, etc.	> Communication >Activities of Daily Living
P45	If the caregiver has the potential to learn, and wants to, and is not undermined by the "system," then she/he implements enhanced techniques and the person with dementia communicates better and shows a reduction in "problem" behaviors.	<Negative behaviors
P46	Less frustration, agitation.	<Frustration
P47	Improved response to cuing Improved targeting of meaningful skills	>Response
P50	Family members like feedback on how they are doing communicating with their loved one.	>Feedback from SLP
P72	Reduced anxiety and frustration	<Anxiety
P75	I have not seen it as I have not been able to incorporate caregivers into the therapy session. I EDUCATE family members when present but have not included them in the therapy session as they are rarely present in the facility.	N/A

Table 4.8 (continued)

Participant	Response	Themes
P76	Same as above	Diet regulation <Falls
P79	It is essential for the primary caregivers to be involved in the tx process. They are the consistent person to be with the client each day and can help develop the consistent routine and appropriate interactions which allow the client to have the most success	>Success
P80	Same as with family -only less	>Understanding
P82	Increased cooperation	>Cooperation
P87	I'm not sure I'm understanding the delineation between caregiver and family member- does this mean paid caregivers?	N/A

Table 4.9

Fisher's Exact Test: Perceived Positive Differences in Individuals with Dementia When Family Members or Caregivers Are Incorporated into Therapy

	0	7	Missing	All
0	4	2	0	6
	0.842	5.158		
	3.441	-1.390		
	11.842	1.933		
7	4	47	2	51
	7.158	43.842		
	-1.180	0.477		
	1.393	0.227		
Missing	0	0	26	*
All	8	49	*	57

Fisher's exact test: $p = 0.0023449$

Table 4.10

Observed Positive Difference in Family Members and Caregivers When Incorporated into Therapy with Individuals with Dementia

Percentage of Frequency	Percentage	(*n*)
Family Members		
Never (0%)	1.69	1
Very Little (1-25%)	3.39	2
No Difference (26-50%)	5.08	3
Some Difference (51-75%)	27.12	16
Great Difference (76-89%)	32.20	19
Consistent Difference (>90%)	28.81	17
Caregivers		
Never (0%)	1.69	1
Very Little (1-25%)	5.08	3
No Difference (26-50%)	8.47	5
Some Difference (51-75%)	33.90	20
Great Difference (76-89%)	32.20	19
Consistent Difference (>90%)	18.64	11

Table 4.11

Participant Anecdotal Comments and Coded Themes Identifies on Types of Positive Difference Observed in Family Members when Incorporated into Therapy with Individuals with Dementia

Participant	Response	Themes
P4	Increased interaction in the loved ones "world"; decrease in arguing with loved one when they don't respond as if in the real world; overall increased communication	>Communication <Arguing
P5	I find family members to be more patient with the individual with dementia when involved in therapy-a greater understanding of the process?	>Patience
P9	Increase in positive interactions, less frustration	<Frustration
P13	Spouse or children report feeling more competent in providing care.	>Confidence
P14	Increased functional interactions with pts with increased knowledge and understanding;	>Interactions >Knowledge
P21	Increased empathy	>Empathy
P23	Family members are less frustrated when they know the behaviors are part of the dementia complex and not due to stubbornness	<Frustration
P25	Families are less frustrated, more compassionate, eager to help and participate in therapy tasks when they see a positive impact on their loved ones	<Frustration >Eagerness to help
P27	Reduced communicative stress (on the part of both communicative partners: the partner with dementia and the caregiver partner)	<Communication stress
P28	Better understanding of dementia and why their family behaves the way they do	>Understanding
P31	They feel they are better able to communicate with their family member and can have a role/purpose with them by understanding their communication	<Role/purpose
P47	Patients are often more verbal	>Verbalization

Table 4.11 (continued)

Participant	Response	Themes
P50	Reports of generalization in use of communication strategies at home with the patient. Communication interactions increase. Often patients begin eating more.	>Generalization >Communication >Food intake
P72	Same as caregivers	<Anxiety
P76	More motivated to help but they are worn down from doing so much	>Motivation
P78	Increased awareness of techniques to incorporate to assist patients	>Awareness
P79	Same as with the caregiver	>Success
P82	Increased knowledge, patience, and attitude.	>Knowledge >Patience

Table 4.12

Participant Anecdotal Comments and Coded Themes of Types of Positive Difference Observed in Caregivers when Incorporated into Therapy with Individuals with Dementia

Participant	Response	Themes
P3	Report decreased stress in dealing with the patient	<Stress
P4	Same as above as well as increase noted in kindness toward the person	>Kindness <Arguing >Communication
P9	Increase in positive interactions	>Interaction
P13	Some patients perform better with family present.	<Performance in therapy
P14	Not as much difference with caregivers ... again as they share their time and energy with several pts	Limited difference
P21	More empathy	>Empathy
P23	Caregivers will not argue with or try to reasons with the demented participant	<Arguing
P27	Reduced communicative stress (on the part of both communicative partners: the partner with dementia and the caregiver partner)	<Stress
P31	Better able to communicate and interact with the patient	>Communication
P33	Although I feel the caregivers would benefit (as would the patient), many of them feel they already know what to do and are frequently not receptive to recommendations (in my experience)	Not receptive
P35	Some caregivers are very appreciative and involved in the learning process.	>Appreciation
P37	feel they are better able to facilitate communication and safe swallowing for the patient	>Communication >Safe swallow
P38	See above box.	>Confidence >Communication pleasure >Patience

TABLE 4.12 (continued)

Participant	Response	Themes
P76	Same as above	>Motivation
P82	Increased knowledge and participation	>Knowledge

Table 4.13

Fisher's Exact Test: Perceived Positive Differences in Family Members and Caregivers When Incorporated into Therapy

	0	7	All
0	6	0	6
	1.241	4.759	
	4.271	-2.181	
	18.241	4.759	
7	6	46	52
	10.759	41.241	
	-1.451	0.741	
	2.105	0.549	
Missing	0	4	*
All	12	46	58

Fisher's exact test: p = 0.0000228

Table 4.14

Frequency of Communication Counsel SLPs Provide to Family Members and Caregivers

Frequency	Percentage	(*n*)
Family Members		
Never (0%)	0.00%	0
Very Little (<20%)	0.00%	0
Rarely (<40%)	8.47%	5
Occasionally (<60%)	16.95%	10
Frequently (<80%)	42.37%	25
Always (100%)	32.20%	19
Caregivers		
Never (0%)	0.00%	0
Very Little (<20%)	1.69%	1
Rarely (<40%)	8.47%	5
Occasionally (<60%)	13.56%	8
Frequently (<80%)	38.98%	23
Always (100%)	37.29%	22

Table 4.15

Fisher's Exact Test: Reported Amount of Communication Counseling Provided to Family Members and Caregivers

	0	7	All
0	3	2	5
	0.508	4.492	
	3.494	-1.176	
	12.208	1.382	
7	3	51	54
	5.492	48.508	
	-1.063	0.358	
	1.130	0.128	
All	12	46	59

Fisher's exact test: p = 0.0056650

Table 4.16

Types of Communication Training/Information Provided to Family Members and Caregivers

Type of Training/Information	Percentage	(*n*)
Family Members		
Never give training or information	0.00	0
Video training	1.69	1
Pamphlets or information from internet resources	49.15	29
Explicit training with family members and individuals with dementia	86.44	51
Workshop training provided for family members	3.39	2
Answer questions if family members approach with concern	76.66	47
Caregivers		
Never give training or information	0.00	0
Video training	0.00	0
Pamphlets or information from internet resources	32.20	19
Explicit training with caregiver(s) and individuals with dementia	84.75	50
Workshop training provided for caregiver(s)	10.17	6
Answer questions if caregiver(s) approach with concern	77.97	56
Recommend interprofessional training (not provided by you)	6.78	4
Provide interprofessional training (by you)	33.90	20

Table 4.17

Anecdotal Comments and Coded Themes Describing Types of Communication Counseling Provided to Family Members

Participant	Response	Themes
P7	Modeling effective communication strategies.	Model
P21	Verbally mediate what I do during session-offer tips	Mediate
P27	I seek out family members or phone them at home about concerns, solicit information about the impact dementia is having & answer questions.	Seek out families Answer questions
P41	Education occurs simultaneously during the therapy session, with examples and practice together with strategies and rationale	Examples Practice
P46	Have family participate in activity with client and me with explicit training.	Participation
P47	Recommendation of books like L Butler, OT's book.	Books

Table 4.18

Anecdotal Comments and Coded Themes Describing Types of Communication Counseling Provided to Caregiver

Participant	Response	Themes
P7	Modeling effective communication strategies.	Model
P27	I seek out care givers about concerns, solicit information about the impact dementia is having & answer questions.	Seek out Answer questions
P41	Education occurs simultaneously during the therapy session, with examples and practice together with strategies and rationale.	Examples Simultaneouslypractice
P47	in-servicing at orientation and impromptu	In-service
P50	The majority of the training is on the spot and during the patient's stay in an acute care setting.	On the spot

Table 4.19

Factors Prohibiting SLPs from Incorporating Family Members and Caregivers into Therapy with Individuals with Dementia

Factor	Percentage	(*n*)
Family Members		
Time	26.32	15
Lack of Training	0.00	0
Lack of available family members	96.49	55
Lack of willing family members	59.65	34
Lack of resources	3.51	2
Reimbursement restrictions	5.26	3
Productivity requirements	15.79	9
Caregivers		
Time	26.32	15
Lack of training	0.00	0
Availability of caregivers	94.74	54
Lack of resources	5.26	3
Reimbursement restrictions	10.53	6
Productivity requirements	15.79	9

Table 4.20

Anecdotal Comments and Coded Themes Describing Factors Prohibiting Participants from Incorporating Family Members into Therapy with Individuals with Dementia

Participant	Response	Themes
P4	Family not living with or near client	living arrangement
P38	I always incorporate family members.	N/A
P41	Availability of family members, both for time of day and for distance, to schedule therapy sessions, even for weekends. Since this is simultaneous with (during) therapy, then resources or time are not relevant factors.	Availability
P46	In home health family often available and I can vary my schedule to be present in home when family available.	Availability
P50	Often family members are from out of town, or all do not come in for training. It is more of catch-as catch-can.	Availability
P76	Productivity rates are out of the roof. Mine is 95%	Productivity
P87	Usually works well as long as the family is available and willing	Availability

Table 4.21

Participant Anecdotal Comments and Coded Themes Describing Factors Prohibiting Participants from Incorporating Caregivers into Therapy with Individuals with Dementia

Participant	Response	Themes
P4	***Training of caregivers is considered part of quality therapy.	N/A
P38	I always incorporate caregivers.	N/A
P41	Same as for family: Availability of family members, both for time of day and for distance, to schedule therapy sessions, even for weekends. Since this is simultaneous with (during) therapy, then resources or time are not relevant factors.	Availability
P46	Lack of willingness of caregiver, scheduling difficulties.	Willingness Scheduling
P50	Often times caregivers will come in for training when family members cannot.	Scheduling
P76	Same as above	Productivity
P82	Willingness to participate	Participation

Table 4.22

Interest in Knowing How to Incorporate Family Members and Caregivers into Therapy

Interest Level	Percent	(*n*)
Family Members		
No interest	6.78	4
Very little interest	3.39	2
Some interest	49.15	29
Definitely	40.68	24
Caregivers		
No interest	6.78	4
Very little interest	1.69	1
Some interest	54.24	32
Definitely	37.29	22