ABSTRACT

ASSESSING THE EFFECTS OF COMMUNICATION COUNSELING FOR CAREGIVERS OF INDIVIDUALS WITH DEMENTIA OF THE ALZHEIMER’S TYPE

by Sharon Kelly Jensen

Caregiver intervention programs may be the only viable option for addressing the cognitive and communicative problems associated with dementia of the Alzheimer’s type (DAT). Because persons with DAT cannot benefit from traditional forms of cognitive-linguistic therapy due to memory deficits, caregiver intervention is needed to ensure positive interactions and continued quality of life. Nineteen professional and family caregivers participated in two sessions of group communication counseling aimed at decreasing caregiver hassles and reports of communication problems. It also focused on increasing caregiver communication knowledge. This research study provided support for the use of caregiver communication counseling as an effective means of increasing caregiver knowledge of communication problems associated with DAT and strategies for their management.
Assessing the Effects of Communication Counseling for Caregivers of Individuals with Dementia of the Alzheimer’s Type

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CHAPTER I

Introduction

Dementia is characterized by a gradual and progressive deterioration of memory, intellectual functioning, and communication. It is a secondary disorder that can be reversible or irreversible. The most common cause of dementia is Alzheimer’s disease (Bayles & Tomoeda, 1990; National Institutes of Health). Alzheimer’s disease causes the formation of neuritic plaques and neurofibrillary tangles in the cerebral cortex. This accumulation of plaque and neurofibrillary tangles causes the loss of crucial neurotransmitters that regulate cortical function. As a result of this cortical damage persons with Alzheimer’s disease (AD) experience dementia and subsequent deterioration of semantic and episodic memory, cognitive functioning and communicative competence (Bayles & Tomoeda, 1990). Dementia caused by Alzheimer’s disease is often described as Dementia of the Alzheimer’s Type (DAT). It is the most common form of dementia seen by speech-language pathologists. Speech-language pathologists are involved in the differential diagnosis of AD and in the evaluation and treatment of DAT (Bayles & Tomoeda, 1990).

Linguistic Deficits Associated with DAT

People with DAT are known to have significant deficits in linguistic communication and conversational skills. Persons with DAT generally present with a mixture of expressive and receptive language deficits (Appell, Kertesz, & Fisman, 1982). Commonly reported symptoms include anomia, verbal perseveration of both words and ideas, and an increased use of non-specific terms, such as “thing”, in place of substantive nouns. Individuals may also exhibit conversational skill deficits, such as poor turn-taking and topic maintenance (Bourgeois, 1992). Persons with Alzheimer’s disease demonstrate conversational language
that is frequently characterized by poorly developed thematic structures (Ripich & Terrell, 1988), tangentiality (Tomoeda & Bayles, 1993) and a reduction in the number of ideas presented (Bayles & Kaszniak, 1987). These deficits in conversational language cause persons with DAT to produce discourse that is confused and lacks a coherence of ideas (Appell et al., 1982). Their speech may be described as “empty” speech (Nicholas, Obler, Albert, & Helms-Estabrooks, 1985). Persons with DAT often demonstrate decreased topic initiation and slowed responses to the initiations of others. Once they have begun to speak, their discourse may be “verbose and circuitous” (Appell et al., 1982). The linguistic output of persons with DAT is continuous and often appears to be quite fluent. However, their discourse is actually incomplete, vague, incoherent or meaningless (Appell et al., 1982).

Language comprehension is also frequently affected by Alzheimer’s disease. Initially, the person with DAT may have difficulty understanding abstract concepts and nonliteral language but be able to comprehend simple conversation. Gradually, as the disease progresses the ability to comprehend and respond to basic language and commands may become impaired (Appell et al., 1982). These problems are the result of the person’s increasing memory disturbance that causes difficulty retaining information that was recently seen or heard (Hopper & Bayles, 2001).

**Communication Breakdown and Caregiver Stress**

Breakdowns in communication between caregivers and persons with DAT are a common cause of stress and burden in daily living (Hirschfield, 1983; Kinney & Stephens, 1989; Levine, Dastoor & Gendron, 1983). Research has shown that caregivers are aware of their loved one’s communication problems and their progression. Caregiver reports have indicated that deficits in linguistic communication are present early in Alzheimer’s disease.
and follow a similar pattern in the majority of cases (Bayles & Tomoeda, 1991). Primary caregivers of persons with DAT indicated that communication with the person with DAT was the greatest problem they faced (Poulshock & Deimling, 1984). Rabins, Mace, and Lucas (1982) interviewed family caregivers of patients with dementia and found that 68% of caregivers cited communicative breakdowns as regular occurrences during interactions with the DAT patient. Of these families that reported experiencing regular communicative breakdowns, 71% felt that these communication difficulties were stressful and problematic.

While families often realize that communication problems are interfering with interactions, they usually do not possess a true understanding of the deficits and their cause. Problematic interactions may be the result of poor understanding of the nature of communication deficits in DAT (Clark & Witte, 1990). They may also result from the lack of caregiver knowledge of effective communicative strategies to decrease miscommunication (Ripich, Ziol, & Lee, 1998). Lack of knowledge of the nature of these communication difficulties coupled with ineffective communication strategies, may cause caregivers to engage in unproductive interactions with the person with DAT. They may misperceive the individual’s communication or develop communicative expectations that are unrealistic (Ripich, Ziol, & Lee, 1998). Continual negative interactions can lead to frustration and anger for both the caregiver and the care recipient.

Professional caregivers, particularly nursing assistants (NAs) have also cited a need for more knowledge of dementia and better communication skills to combat job-related stress and decrease high turnover rates in long-term care facilities (Burgio & Burgio, 1990; Ripich, Wykle, & Niles, 1995; Caudill & Patrick, 1991-1992). Two of the most common stressors reported by NAs were disruptive resident behaviors and a shortage of trained staff in nursing
homes (Burgio, Butler, & Engel, 1988; Chappel & Novak, 1992). Nursing assistants also listed a need for instruction in managing problem behaviors and addressing patients’ mental health issues (Burgio et al., 1988; Carstensen & Fisher, 1988). A qualitative survey conducted by Moran (1996) reported that the primary area of need in nursing assistant education programs was interpersonal skills with patients and coworkers. Specifically, NAs reported that more education was needed to improve their understanding and management of patients with dementia and other cognitive impairments. In addition, other surveys of NAs indicated that additional training would be welcome and that more training in the effective care of dementia patients would likely increase their job satisfaction (Caudill & Patrick, 1991-1992; Maas, Buckwalter, Swanson, & Mobily, 1994; Moran, 1996; Ripich, Wylke & Niles, 1995).

Maas, Buckwalter, Swanson, and Mobily (1994) compared training levels and job satisfaction for registered nurses (RNs) and non-RN staff. They also compared staff on special care units and AD units with staff on traditional long-term care facility units. Regardless of placement on special care units or traditional units, RN staff were more satisfied than non-RN staff. This may be due to a higher level of relevant training and therefore better job performance. Conversely, the non-RN staff who worked with AD patients either on special care units or on traditional units were not as satisfied with their training and preparation. The results of this study support the need for further training for nursing staff in long-term care facilities. Training is particularly needed to increase knowledge of AD and the care of patients with the disease. It also suggested that job satisfaction was linked to the level of staff training and its effects on job stress.
The Effects of Caregiver Intervention

There are a variety of caregiver interventions that are aimed at reducing caregiver stress, increasing positive interactions with care recipients, and preventing care-recipient institutionalization. These include support groups, educational programs, both individual and group counseling, communication training, multi-component programs for family caregivers, and communication and memory aid training for professional caregivers. Comprehensive reviews of these types of dementia and AD interventions have shown positive results for the majority of these treatments (Bourgeois, Schulz, & Burgio, 1996; Burgio et al., 2000; Knight, Lutzky, & Macofsky-Urban, 1993; McCallion Toseland, Lacey, & Banks, 1999; Ripich, Wykle, & Niles, 1995; Toseland & Rossiter, 1989).

Support groups are an arena for family caregivers to discuss their problems and concerns related to caregiving with others who share similar knowledge and situations. Research regarding the benefits of support groups in increasing caregiver well-being, however, has been unclear due to the use of subjective and unspecified outcome measures. Despite these concerns, these groups have shown positive effects as a means of educating, sharing information, and creating social support networks (Bourgeois, Schulz, & Burgio, 1996; Toseland & Rossiter, 1989).

Both group and individual counseling have demonstrated effects in helping family caregivers deal with stress and emotional issues related to caregiving responsibilities. Overall, individualized counseling approaches for family caregivers have been more effective than group counseling. Both have been effective in decreasing stress and burden, and in addressing psychological factors related to caregiving (Bourgeois, Schulz, & Burgio, 1996; Knight, Lutzky, & Macofsky-Urban, 1993).
A large portion of caregiver intervention research examines various combinations of the above approaches. Multi-component programs that include family and individual counseling, home visits, and support group participation have also shown success in reducing stress and delaying institutionalization of AD patients (Ferris, Steinberg, Shulman, Kahn, & Reisberg, 1987; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996). However, it is difficult to determine which aspects of these programs were responsible for changes in caregiver stress levels and delayed institutionalization.

Group communication training for family caregivers has also proven successful in decreasing communication hassles, increasing positive interactions, and reducing caregiver stress (McCallion, Toseland, & Freeman, 1999; Ripich, Ziol, & Lee, 1998; Shulman & Mandel, 1988). These interventions focused on specific skills training in communication and education about AD and resulting communication changes. The purpose of the training was to reduce negative caregiver feelings and interactions and increase positive exchanges between caregivers and their loved ones with DAT.

In addition, recent research efforts have focused on the effects of communication skills and memory aid training for professional caregivers of persons with dementia (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001;Burgio et al., 2000; McCallion, Toseland, Lacey, & Banks, 1999; Ripich, Wylke, & Niles, 1995). These studies have shown that training nursing staff to use memory aids and communication techniques with patients with dementia can be effective in decreasing patient behavior problems, improving staff knowledge of dementia, and improving attitudes towards patients with dementia.
Statement of the Problem

Research has shown that stress and hassles related to caregiving responsibilities are a significant problem for both family and professional caregivers (Burgio & Burgio, 1990; Caudill & Patrick, 1991-1992; Hirshfield, 1983; Kinney & Stephens, 1989; Levine, Dastoor, & Gerdon, 1983). This stress can lead to negative caregiver-care recipient interactions, which creates frustrations for both groups of caregivers and decreases job satisfaction for professional caregivers. A variety of caregiver intervention programs have been implemented to decrease these problems and increase positive outcomes for persons with AD and their caregivers.

There is a significant amount of research (Chiverton & Caine, 1989; Gallagher-Thompson & Steffen, 1994; Kahan, Kemp, Staples, & Brummel-Smith, 1985; Lazarus, Stafford, Cooper, Cohler, & Dysken, 1989; Schimdt, Bonjean, Widem, Scheft, & Steele, 1988; Shulman & Mandel, 1988; Ripich, Wylke, & Niles, 1995; Ripich, Ziol, & Lee, 1998; Toseland & Smith, 1990) regarding support groups, individual counseling, multi-component programs, and group communication training. However, there is little research that investigates the effects of communication counseling for caregivers of people with DAT in reducing caregiver stress and communication hassles. In addition, a large portion of the research (Gallagher-Thompson & Steffen, 1994; McCallion, Toseland, & Freeman, 1999; Toseland, Rossiter, & Labreque, 1989; Toseland, Rossiter, Peak, & Smith, 1990; Toseland & Smith, 1990) in these areas has examined the effects of long-term programs and interventions. In today’s cost-conscious health care environment, it is important to determine the effects of various amounts of caregiver interventions in increasing caregiver well-being. There must also be careful investigation of specific skills training and components of multi-
intervention programs to determine what aspect of intervention is most effective in decreasing caregiver stress and increasing positive caregiver-care recipient interactions. There is also a need to compare the effects of specific intervention models on family and professional caregivers. By comparing the outcomes of specific caregiver interventions on these two groups we can determine the model that is most effective for each group. For these reasons it is imperative that information be available regarding the effectiveness of short-term, caregiver communication counseling for improving communication and decreasing daily hassles of both family and professional caregivers.

**Purpose of the Study**

The purpose of this study was to examine the effectiveness of communication counseling in (a) decreasing daily caregiving hassles, (b) improving caregiver-care recipient communication, and (c) increasing caregiver knowledge of communication problems associated with DAT and their management. This study investigated the level of hassle associated with caring for persons with DAT and the types of communication problems that occurred between caregivers and care recipients.

**Significance of the Problem**

This study was designed to determine the significance of the effects of communication counseling on family and professional caregivers of persons with DAT. Currently, there is a small amount of research (Ripich, Ziol, & Lee, 1998) examining the effectiveness of communication counseling in reducing caregivers’ feelings of stress and hassle with persons with DAT. In addition, there is only a small amount of research (Burgio et al., 2000; McCallion, Toseland, & Freeman, 1999; Shulman & Mandel, 1988; Ripich, Wylke, & Niles) that investigated the effects of communication training on caregiver-care...
recipient communication. While there are numerous studies (Gallagher-Thompson & Steffen, 1994; Haley, Brown, & Levine, 1987; Lazarus et al., 1989; Marriot, Donsaldson, Tarrier, & Burns, 2000; Schmidt et al., 1988; Toseland, Rossiter, & Labreque, 1989) examining various types of family caregiver intervention and professional caregiver communication training, few have examined the effects of these programs in reducing stress and increasing positive attitudes and interactions with dementia patients. Currently the researcher is not aware of any research comparing the effectiveness of short-term communication counseling for both professional and family caregivers. This study investigated the benefits of a group counseling approach aimed at increasing positive communicative interactions and thereby reducing caregiver’s daily hassles. Positive results would demonstrate a reduction in caregiver hassle and stress, thereby providing support for the use of caregiver communication counseling programs as a means of improving caregiver and patient interactions and quality of life. Comparing the effects of communication counseling on both family and professional caregivers could provide insight into what type of intervention is most appropriate for different caregiver populations. It may also stimulate further research in the area of communication counseling.

Chapter Summary

In this chapter DAT and its effects on linguistic communication were discussed. The nature of caregiver stress and burden related to breakdowns in communication with persons with DAT was also examined. The purpose of this study was identified, that is, to determine the effectiveness of communication counseling in (a) decreasing daily caregiving hassles, (b) improving caregiver-care recipient communication, and (c) increasing caregiver knowledge of communication problems associated with DAT and their management.
CHAPTER II
Review of the Literature

Clinically, it has been noted that the relationship between caregivers and persons with DAT is improved when caregivers are knowledgeable about the cognitive and communicative deficits associated with dementia (Bayles & Kaszniak, 1987). Counseling, educating and training caregivers and family members is an important aspect of treatment for the speech-language pathologist working with persons with DAT. Since patients with AD may be unable to benefit from traditional communication treatment, caregiver intervention may be the only treatment available to those dealing with DAT.

*Multi-Component Interventions for Caregivers*

Several research studies (Ferris, Steinberg, Shulman, Kahn, & Reisberg, 1987; Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996) have described the effects of multi-component intervention programs to educate and train caregivers of persons with DAT and frail elderly persons. These programs combine various approaches to caregiver intervention into one program aimed at improving caregiver-care recipient relationships, reducing caregiver stress, or delaying nursing home placement.

Mittleman, Ferris, Shulman, Steinberg, & Levin (1996) described the effects of one such program aimed at delaying nursing home placement of persons with AD. Their treatment program consisted of a combination of individual and family counseling, support group participation, and continuous telephone access to counselors. Subjects receiving this treatment were found to be two-thirds less likely to place their relative with AD in a nursing home as subjects in a control group. Although, this study does support the effectiveness of
caregiver intervention, it fails to indicate which component of the program was responsible for the positive outcomes.

Kahan, Kemp, Staples, & Brummel-Smith (1985) also described the effects of a multi-component caregiver intervention program. Forty-four family members of AD outpatients were provided with weekly group education and support sessions that involved a variety of treatment approaches. Twenty-two experimental subjects received eight two-hour sessions weekly. These sessions were broken into 1 hour of didactic teaching about AD and 1 hour of group discussion. Treatment sessions included training in stress management and role-playing activities. Analysis of pre/post intervention measures indicated a significant increase in knowledge of dementia and a reduction in caregiver burden and depression. These results were further supported by verbal reports of better family relationships and behavioral changes in caregiving skills from caregivers.

Marriott, Donaldson, Tarrier, and Burns (2000) researched the effects of family intervention for caregivers of persons with AD that included education, stress management and coping skills training. Subjects receiving this intervention were compared with two control groups. The first control group participated in an in-depth family interview, while the second control group did not. Fourteen caregivers and their care recipients participated in the family intervention and each control group also consisted of 14 subjects. Results of this study found that there was a significant decrease in distress and depression for subjects receiving the family intervention in comparison with controls at post-treatment and follow-up. The subjects also reported significant reductions in behavior problems. No significant differences were found between the two controls groups in caregiver distress and depression. Despite
positive intervention outcomes, this study failed to indicate what aspect of treatment was most effective.

Haley, Brown, & Levine (1987) compared the effects of educational support groups alone with support groups in combination with relaxation training and stress management skills training. These treatments were also compared with a control group of subjects on a treatment waiting list. Fifty-four family members caring for a person with AD were recruited from a local AD society, media publicity, and social service referrals. All subjects in treatment groups participated in ten 90-minute weekly group sessions. Group one participated in an educational support group only, while group two participated in an educational support group and received relaxation and stress management training. No difference was found between treatment groups and the control group on outcome measures but both treatments were given positive verbal ratings from caregivers. Both treatments were cited by caregivers as being useful in addressing caregiving concerns. Again, it cannot be determined which component of the treatment program subjects in group two found more beneficial.

While each of the above studies did result in improved caregiver outcomes it is impossible to determine which treatment approach was responsible for these changes. It cannot be determined which intervention (group counseling, individual counseling, support group participation, stress management training, coping skills training, or relaxation training) was responsible for the positive outcomes of these studies. For information regarding the effects of specific caregiver intervention approaches on decreasing caregiver stress and burden and increasing positive caregiver-care recipient relations, we must look at specific research regarding support groups, individual counseling, and group communication training.
Caregiver Support Groups

Early support group intervention research is highly descriptive in nature and frequently only reports suggestive information about the effectiveness of support groups in changing outcomes, such as perceived stress and burden, locus of control, and emotional ability to deal with caregiver responsibilities (Bourgeois, Schulz, & Burgio, 1996). Despite reports of positive outcomes the majority of outcome measures resulting from support group literature is based primarily on verbal reports of caregivers’ survey responses, and clinical impressions.

Later research into the effects of support groups found that while this type of caregiver intervention increased social support networks and emotional coping abilities, it did not result in decreased family caregiver stress or burden. Chiverton and Caine (1989) compared 20 caregivers of patients with AD who received three 2-hour group education sessions with 20 control subjects over a four-week intervention period. Comparisons of pre/post coping measures showed an increase in the treatment groups knowledge of AD and their emotional competence.

Lazarus, Stafford, Cooper, Cohler, and Dysken (1989) also compared subjects in a support group with control subjects. These researchers compared four subjects receiving 10 one-hour support group sessions with 3 subjects who were not participating in a support group. Post treatment results showed an improvement on locus of control measures for the support group subjects, that was not seen in control subjects. However, no significant differences were noted between the two groups on measures of anxiety and depression.

Toseland, Rossiter, and Labrecque (1989) compared the treatment effects of 18 subjects in a professionally-led support group with those of 18 subjects in a peer-led support
group. Effects for the two treatment groups were also compared with a control group. All subjects were daughters or daughters-in-law of frail elderly patients. All experimental subjects participated in eight weekly 2-hour support group sessions. Both the professionally-led and peer-led support groups showed significant improvement in psychological functioning, an increase in informal support networks, and positive personal changes. However, the professionally-led group had a greater increase in psychological functioning, while those in the peer-led group had a greater increase in informal support networks. There was a small increase in burden for the subjects in the control group. No decrease in burden was seen for either treatment group.

The above studies demonstrate the effectiveness of group support in increasing informal social support, psychological functioning, and emotional coping skills of family caregivers of elderly patients with and without dementia. However, none of these groups was successful in decreasing daily burden and stress of family caregivers. Even professionally-led support groups were not effective in decreasing daily hassles and burdens of these caregivers. While these studies do support the effectiveness of group intervention for family caregivers in increasing social support networks and coping skills they do not address the day-to-day hassles of family and professional caregivers associated with caring for patients with dementia and other neurological diagnoses.

Individual and Group Caregiver Counseling

There has been a variety of research (Gallagher-Thompson & Steffen, 1994; Schmidt et al., 1988; Toseland & Smith, 1990; Toseland, Rossiter, Peak, & Smith, 1990) describing individual and group counseling for family caregivers of persons with AD and other frail elderly. A portion of this research (Aronson, Levin, & Lipkowitz, 1984; Nathan, 1986) is
descriptive in nature. However, more controlled research involving individual counseling has shown it to be an effective treatment for decreasing caregiver burden and stress.

Gallagher-Thompson and Steffen (1994) compared the effectiveness of two forms of psychotherapy. Sixty-six depressed family caregivers of frail elderly persons were randomly assigned to either a cognitive/behavioral counseling group or a psychodynamic counseling group. Sixty-two percent of caregivers were caring for persons with AD. Subjects in both groups received 16-20 individual psychotherapy sessions. Assessment of subject outcomes was completed at 10 weeks during treatment, immediately post-treatment, and at both 3 and 12-months post-treatment. Both forms of psychotherapeutic counseling were successful in resolving depression in 71% of subjects. There were no differences between the two treatment types. There was a treatment by length of caregiving effect. Caregivers who cared for their elderly relative for three and one-half years or more benefited more from cognitive/behavioral therapy and those caregivers with less time caregiving received greater benefit from psychodynamic therapy. While this study does describe the effectiveness of individual counseling in decreasing caregiver depression, it does not address issues of caregiver hassle and burden or improved caregiver-care recipient interactions.

Schmidt, Bonjean, Widem, Scheft, & Steele (1988) randomly assigned 20 caregivers of persons with dementia to one of two individual psychotherapy groups. Group one received psychotherapeutic counseling focused on individual problem-solving of caregiver hassles and burdens associated with caregiving. Group two received psychotherapeutic counseling that focused on both individual problem-solving and emotional expression of feelings related to caregiving. Results of this comparison only indicated a significant difference between the two groups on one outcome measure. Group two was found to have decreased psychiatric
symptoms and an improved relationship with the care recipient. All other measures indicated similar results for both treatments. Unfortunately there was no comparison with a control group to further measure treatment effects. However, this research does provide support for the effectiveness of individual counseling and problem-solving approaches in improving relations between caregivers and their care recipients.

Toseland and Smith (1990) also described the effects of individual counseling on caregiver-care recipient interactions. They examined the effects of counseling versus no counseling with 87 daughters and daughters-in-law serving as primary caregivers of frail elderly persons. Twenty-seven subjects received professionally-led individual counseling, 24 subjects received peer-led individual counseling, and 36 subjects received no counseling. All experimental subjects received 8 weekly 1-hour individual counseling sessions. Overall, those subjects in the professional counseling group had better treatment outcomes in the areas of subjective well-being, level of psychiatric symptoms, and perceived change in caregiver-care recipient relationship than those subjects in the peer counseling group. No treatment effects were seen in formal or informal support networks for either experimental group.

Toseland, Rossiter, Peak, & Smith (1990) compared results of previous studies (Toseland, Rossiter, & Labreque, 1989; Toseland & Smith, 1990) of group and individual counseling with control subjects. Sixty-seven subjects who received weekly two-hour group counseling for eight weeks were compared with 51 subjects who received eight weekly 1 hour individual counseling sessions. Both groups were compared with 36 subjects in a control condition. Results showed that those in the individual counseling group had more positive treatment outcomes in areas of psychological functioning and well-being than those
receiving group counseling. However, subjects in group counseling demonstrated greater improvement in social support. Both treatment groups experienced significant improvements in coping with stress related to caregiving when compared with controls.

The research above illustrates the positive effects of individual counseling of caregivers of persons with dementia and other frail elderly individuals. Overall, individual counseling of caregivers has been shown to increase feelings of well-being, decrease psychiatric symptoms, decrease caregiver stress, and improve caregiver-care recipient relationships. Comparisons with group counseling, however, showed that group counseling was more effective in fostering feelings of social support and that both counseling formats are effective in caregiver stress reduction. Another type of caregiver intervention that has demonstrated positive results in decreasing caregiver hassles and burden and improving interactions with care recipients is group communication training.

*Communication Training for Caregivers*

As the cognitive and communicative skills of the person with DAT progressively decrease, caregivers often find themselves focusing on the physical care of persons with DAT and dealing with problem behaviors. They may resign themselves to unproductive or nonexistent communicative interactions (Haley, Levine, Brown, Berry, & Hughes, 1987). In order to alleviate caregiver burden and increase positive patient-caregiver interactions, caregivers need specific training in communication strategies that will allow them to facilitate positive communicative interactions with their loved ones (Bourgeois, 1991). This is true for both family and professional caregivers. Caregiver intervention focusing on communication training allows persons with dementia to engage in successful communication partnerships and reduce some caregiver stress.
Shulman and Mandel (1988) described the effects of a group communication training program for caregivers of elderly individuals in institutional settings. The goals of this program were to change attitudes and behaviors of family caregivers, increase their use of communication facilitating techniques, and increase appropriate expectations for interactions with their loved ones. The primary goal of the training program was to increase the probability of positive visits with elderly relatives. Participants were trained in the nature of communication, the effects of age and disease on communication, and management techniques for dealing with breakdowns in communication. Following their participation in the program, 86% of participants reported that they were having better visits with their elderly relatives. Seventy-eight percent reported that they had improved knowledge of communication problems, their consequences and management (Shulman & Mandel, 1988).

McCallion, Toseland, and Freeman (1999) developed a program for improving family visits. Their Family Visit Education Program focused on improving communication among residents, nursing staff, and visiting family members in nursing homes. The study was conducted in five skilled-care nursing homes that ranged in size from 120 to 300 beds. Sixty-six residents and their primary visitor were randomly assigned to the treatment or control groups. Subjects in the Family Visit Education Program were measured at baseline, 3 months, and 6 months for psychosocial functioning, depression, agitated behavior, and social interaction. The program showed benefits for residents and their family members. Family members were noted to have improved communication patterns with the nursing home residents, while the residents demonstrated improvement in irritability, verbal behavior and depression. These effects were not seen in a control group. A reduction in the use of
mechanical restraints by nurses was also noted. This program was not effective in changing
the communication style of nurses with residents.

Ripich, Ziol, and Lee (1998) studied the longitudinal effects of one approach to
communication training for family caregivers. Nineteen family caregivers participated in the
FOCUSED communication training program. Results for these experimental subjects were
compared with 18 subjects in a control group. An adapted version of The Alzheimer’s
Disease Communication Guide: the FOCUSED Program for Caregivers (Ripich, 1996) was
used to educate experimental subjects about AD and communication. The training included a
series of group educational sessions and focused on (a) correcting misperceptions about
communicative interactions with persons with AD, and (b) training caregivers in techniques
to increase positive and effective communication between caregivers, family members, and
the person with AD. Results indicated that caregivers who participated in the FOCUSED
program showed a significant increase in knowledge of AD and communication, and a
decrease in communication hassles, over time (Ripich, Ziol, & Lee, 1998). At 6 months post-
training participants reported a decrease in communication hassles and this decrease was
maintained after 12 months post-training. The increases in knowledge were noted
immediately following training and were consistent at both 6 and 12-month follow-ups. The
control group was found to have an increase in communication hassles. It was found that the
main effects of the FOCUSED program were related to improved communication.

Communication training of professional caregivers has also been shown to be
effective in improving resident behavior, increasing patient-caregiver interactions, and
increasing staff knowledge about dementia. In 1995, Ripich, Wylke, and Niles studied the
effects of the FOCUSED communication training program on certified nursing assistants
(CNAs) and nursing home residents. The CNA’s were trained in the same FOCUSED communication training strategies described previously. Subjects were seventeen nursing assistants working in long-term care facility. Training was divided into six, two-hour training modules. Training modules covered the following topics: AD and communication decline, differences between depression and AD, the value of interpersonal skills in caregiving, cultural and ethical considerations in communication with AD residents, the stages of AD and communication, and the use of the FOCUSED techniques. Results indicated that training in the FOCUSED communication techniques resulted in greater knowledge of dementia and improved attitudes towards patient with dementia. The most significant gains in knowledge were seen in information discussed in modules five and six that taught the FOCUSED strategies. The CNAs reported greater satisfaction in communication with patients with AD on post-training measures.

McCallion, Toseland, Lacey, and Banks (1999) developed and evaluated a Nursing Assistant Communication Skills Program (NACSP). The NACSP was designed to help nursing assistants (NAs) have better interactions with nursing home residents with dementia. The program was implemented in two skilled care nursing homes, with NAs randomly assigned by unit to NACSP or a wait-list control. Eighty-eight NAs participated in the program. The NACSP consisted of five 45-minute group sessions and four 30-minute individual conferences delivered by a master’s level social worker. The NACSP addressed knowledge of dementia, verbal and nonverbal communication, use of memory aids, and problem behaviors. Results showed that participation in NACSP by NAs improved their ability to deal with verbally aggressive patient behaviors for both 3 and 6 months post-training. Some support for the NA’s increased knowledge of dementia and ability to deal
with problem behaviors was also demonstrated. Throughout the study there was a consistent decrease in staff turnover in the NACSP trained NAs.

Burgio, et al., (2000) examined the effects of communication skills training and the use of memory books by CNAs on communicative interactions with nursing home residents. Sixty-four CNAs participated in this program. The CNAs were taught to use both specific communication skills and memory books during routine care interactions with nursing home residents with cognitive impairments. A staff motivational program was also used to encourage use of these skills. The subjects receiving the training were compared with those on individuals from control units. The results of the study indicated that trained CNAs talked more, used a greater amount of positive communication, and gave more specific instructions to residents than control subjects. It was also noted that use of these communication skills and memory books did not increase caregiving time. These results were maintained at two months post-training.

Allen-Burge, Burgio, Bourgeois, Sims, and Nunnikhoven (2001) also evaluated the effects of a communication skills and memory book program. Twelve CNAs and three licensed practical nurses (LPN) employed in a university-owned nursing home were taught to use communication skills and memory books while interacting with nursing home residents with mild to moderate cognitive impairments. Intervention occurred over a period of 5 weeks. Intervention included both in-service and hands-on training. Research measures and observation showed that CNAs could improve their communication skills and learn to use a memory book with residents. Results of the study indicated that even with sporadic implementation of the intervention by nursing staff, improved communication between staff and residents occurred during care routines. An increase in the amount of time CNAs spent
talking with residents and their visitors was also noted. Residents participating in this research used more positive statements when nursing staff implemented the learned communication skills and used memory books.

Chapter Summary

The above studies described a variety of successful caregiver interventions. Both counseling and group communication training have been shown to be effective in reducing caregiver stress and hassles and improving caregiver-care recipient relationships. Unfortunately, there is no available research that examines the combination of these two effective caregiver intervention approaches. Since both counseling and communication training have been shown to be effective caregiver interventions, it would be expected that communication training offered in a counseling format would produce even greater positive outcomes in reducing caregiver hassles by improving interactions with care recipients.
CHAPTER III

Methods and Procedures

Subjects

The subjects were 13 professional caregivers of 19 individuals who had been diagnosed with DAT in an assisted living center and 6 family caregivers of some of those same individuals with DAT. Subjects were recruited from the McKnight Terrace Assisted Living Center in Middletown, Ohio. (See Appendix A). Subjects were selected according to inclusion and exclusion criteria.

Inclusion Criteria

Subjects were either professional staff at the McKnight Terrace Assisted Living Center in the Alzheimer’s Unit or a relative of a resident in this unit who had been diagnosed with AD and was suffering from dementia. The residents, or care recipients, were identified as having a physician’s diagnosis of probable AD and dementia, and presented with deficits in memory, communication and one other area of cognitive functioning.

Exclusion Criteria

Subjects were excluded from the study if they did not work in the Dementia Unit or if their family member with DAT had a primary diagnosis other than AD with dementia or was not a resident of the McKnight Terrace Alzheimer’s Unit. Individuals who were participating in another caregiver training program or whose relative with DAT was receiving speech-language therapy were excluded from study. Professional caregivers who had specialty training in communication or other relevant areas were also excluded.
Confidentiality of Records

Each subject was referred to by a designated number throughout the study. None of the results included any identifying information. All data was stored in a locked file cabinet. The researcher and research advisor were the only individuals who had access to a subject’s identifying information. This information was locked in a separate file cabinet from the one that contained individual data.

Procedures

If subjects met inclusion criteria they were asked to participate in this study. Subjects were grouped into family caregivers (N = 6) and professional caregivers (N = 13) for comparison.

Pre-Intervention Measures

Prior to any collection of data both the professional and family caregivers received a brief explanation of the study and were asked to sign a consent form (Appendix B). Subjects were assured of the confidentiality of all data and personal information. To determine each caregivers’ level of daily stress and burden related to their caregiving responsibilities, each subject completed the modified Caregiver Hassle Scale (Kinney & Stephens, 1989) (Appendix C). The subjects also completed a Communication Perceptions Questionnaire (Appendix D), designed by the researchers to determine what types of communication problems the subjects were experiencing with the individual(s) with DAT and how these problems affected them. Two versions of this questionnaire were administered according to group placement, professional caregiver or family caregiver. Finally, all subjects completed a Knowledge Survey (Appendix E) to determine their pre- and post-counseling knowledge of communication strategies and Alzheimer’s disease.
Communication Counseling Sessions

Both professional and family caregivers were seen in separate group communication counseling sessions. Both the groups of caregivers participated in two, 90 minute group communication counseling sessions during a 2-week period. The communication counseling sessions were based on modules five and six of the Alzheimer’s Disease Communication Guide: The FOCUSED Program for Caregivers (Ripich, 1996). For each group, the first communication counseling session (Appendix F) focused on providing instruction in the FOCUSED communication strategies. Subjects also were given the opportunity to explore their emotional reactions and hassles related to their caregiving responsibilities. Subjects received a written handout that included a description of these techniques and practice exercises (Appendix G). The second communication counseling session (Appendix H) was completed two weeks after the initial session. Counseling during the second session focused on communication goals and specific strategies used at the different stages of DAT. An additional handout was provided that reviewed this information (Appendix I). During the second session subjects were presented with problem-solving opportunities regarding communication difficulties with patients with DAT. Additional information regarding other strategies for dealing with communication breakdowns and improving caregiver-patient interactions was also provided at the conclusion of this session (Appendix J).

Post-Intervention Measures

Following the second session subjects were re-administered the modified Caregiver Hassle Scale (Kinney & Stephens, 1989) and Communication Perceptions Questionnaire. All subjects also completed a post-intervention Knowledge Survey regarding the training they received. The numeric data from the post-intervention Caregiver Hassle Scale and
Communication Perceptions Questionnaire were compared with pre-intervention measures to assess any differences in caregiver-care recipient communication and caregiver hassles. Family versus professional caregiver data was also compared. Pre- and post-intervention scores on the Knowledge Survey were used to determine information gained from training and to compare family versus professional caregiver knowledge.

Assessment Tools

*Caregiver hassles scale.* The Caregivers Hassle Scale (Appendix C) (Kinney & Stephens, 1989) assesses the daily hassles of caring for a family member with Alzheimer’s disease. It differs from other caregiving stress and burden scales by concentrating on the small events of day-to-day caregiving, rather than the effects of caregiving over a long period of time. The Caregiver Hassle Scale (Kinney & Stephens) consists of 42 items that are possible caregiving hassles. The items are divided into five categories of potential stressors: (a) those associated with basic activities of daily living, (b) instrumental activities of daily living, (c) the care-recipient’s cognitive status, (d) the care-recipient’s behavior and, (e) the caregivers’ support network. Scoring of individual items was modified to accommodate the research design of this study. The caregiver determined which of these 42 items had been a hassle in the recent past (“yes” response) and then rated the level of hassle on a scale of 1 to 4, one being *not at all* and four being *a great deal* of hassle. Pre/post-intervention ratings were compared for each question that received a “yes” response on the pre-intervention scale.

*Communication perceptions questionnaire.* The Communication Perceptions Questionnaire, designed for the present study, focused on gathering qualitative and quantitative information about caregivers’ attitudes related to their caregiving responsibilities and communication with the person with DAT. It also focused on what types of
communication problem the caregivers were having with individuals with DAT. Two versions of this questionnaire were used according to the specific subject group. Some questions were adapted from the FOCUSED program (Ripich, 1996) attitudes survey.

Knowledge survey. A modified version of the Knowledge Survey from the FOCUSED program (Ripich, 1996) was used to determine learning outcomes of the communication counseling sessions. Scores on this survey were also used to compare family and professional caregivers and assess possible differences in learning and understanding of communication counseling information.

Experimental Design

A pre versus post-intervention research design was used to evaluate possible differences between caregiver hassles and communication perceptions following communication counseling for caregivers of individuals with DAT. The outcome measures used to determine any differences were the pre- versus post-intervention numeric data from the Caregiver Hassle Scale, Communication Perceptions Questionnaire, and Knowledge Survey. Comparisons of the professional versus family data were made.
Research Questions

1. Will communication counseling intervention have a significant effect on reports of caregiving hassles by family caregivers’ of persons with DAT?

2. Will communication counseling intervention have a significant effect on reports of caregiving hassles by professional caregivers’ of persons with DAT?

3. Is there a significant difference between family and professional caregivers’ reports of caregiving hassles?

4. Will communication counseling intervention have a significant effect on perceptions of communication problems of family caregivers’ of persons with DAT?

5. Will communication counseling intervention have a significant effect on perceptions of communication problems of professional caregivers’ of persons with DAT?

6. Is there a significant difference between family and professional caregivers’ perceptions of communication problems?

7. Will communication counseling intervention have a significant effect on knowledge of communication strategies of family caregivers’ of persons with DAT?

8. Will communication counseling intervention have a significant effect on knowledge of communication strategies of professional caregivers’ of persons with DAT?

9. Is there a significant difference between family and professional caregivers’ knowledge of communication strategies?
Null Hypotheses

1. Communication counseling intervention will not have a significant effect on reports of caregiving hassles by family caregivers of persons with DAT.

2. Communication counseling intervention will not have a significant effect on reports of caregiving hassles by professional caregivers of persons with DAT.

3. There will not be a significant difference between family and professional caregivers’ reports of caregiving hassles.

4. Communication counseling intervention will not have a significant effect on perceptions of communication problems of family caregivers of persons with DAT.

5. Communication counseling intervention will not have a significant effect on perceptions of communication problems of family caregivers of persons with DAT.

6. There will not be a significant difference between family and professional caregivers’ perceptions of communication problems.

7. Communication counseling intervention will not have a significant effect on knowledge of communication strategies of family caregivers of persons with DAT.

8. Communication counseling intervention will not have a significant effect on knowledge of communication strategies of professional caregivers of persons with DAT.

9. There will not be a significant difference between family and professional caregivers knowledge of communication strategies.
Statistical Analysis

Participants’ scores on the pre- and post-intervention measures of caregiver hassles, communication problems, and strategy knowledge were compared using paired t-test comparisons. A comparison of family versus professional caregivers’ improvement scores (pre- to post-intervention) was analyzed using independent samples t-test. The alpha significance level was set at $p < 0.05$. Qualitative data gathered from the Communication Perceptions Questionnaire was categorized based on similarity of response.

Chapter Summary

In this chapter the methods for subject participation were explained and the sample size of 19 caregivers of individuals with DAT was described. This chapter also stated that the subjects were recruited from the McKnight Terrace Assisted Living Center–Alzheimer’s Unit in Middletown, Ohio. The research procedures for the collection of data and experimental design were defined. In addition, the research questions and null hypotheses were stated.
CHAPTER IV

Results

Subject Demographics

Nineteen subjects participated in this investigation. Subjects were recruited at McKnight Terrace Assisted Living Center in Middletown, Ohio. The inclusion criteria for this study were that participants be employed as professional caregivers at McKnight Terrace Alzheimer’s Unit or relatives of a resident in the Alzheimer’s Unit. Eighteen individuals with dementia of the Alzheimer’s Type (DAT) were residing in the Alzheimer’s Unit. One individual with DAT was not a permanent resident on the Alzheimer’s Unit but received day care services. Of these residents 3 were males and 15 were females. Residents’ ages ranged from 78 to 99 years, and the average length of residency at the time of intervention was two years. Most residents were experiencing symptoms of DAT in the moderate and severe stages.

Thirteen professional caregivers employed at McKnight Terrace Alzheimer’s Unit and six family caregivers of residents on this unit participated in this study. All of the professional caregivers and four out of six family caregivers were females. The mean age of both subject groups was 48 years ($SD = 11$, range 21-73). Among professional caregivers the mean age was 45 years ($SD = 12$, range 21-63). The mean age of family caregivers was 55 years ($SD = 22$, range 46-72).

Professionals’ highest level of education varied. Seven of the professional caregivers were certified nursing assistants (CNAs), and three were licensed practical nurses (LPNs). Another subject was a state tested nursing aide. One subject held an associate’s degree in nursing but was not board certified. One other professional caregiver had no formal training,
but had completed an Alzheimer’s workshop. Several subjects reported they had received some in-service training related to Alzheimer’s disease. The mean length of caregiving for professional caregivers was 8 years (SD = 2 years, range 3-27).

The highest level of education held by a family caregiver was a master’s degree. One subject had a Bachelor of Science degree, and a third subject had three years of college. Of the remaining subjects, one was a licensed optician, another had a high school diploma, and one other listed no degree or certification. None of the family caregivers reported holding any specialty training related to Alzheimer’s disease or dementia. The mean length of time since the family caregivers’ loved ones were diagnosed with DAT was 2 years (SD = 10 months, range 6 months-7 years).

Descriptive and Inferential Statistics for Research Questions

Research Question 1: Will communication counseling intervention have a significant effect on reports of caregiving hassles by family caregivers of persons with DAT?

In order to analyze this question, paired t-test comparisons were made of subjects’ pre- and post-intervention scores for items with “yes” responses on the pre-intervention Caregiver Hassles Scale (Kinney & Stephens, 1989). The t-test analysis determined that the mean change, reported in Table 1 (Appendix K), between pre- and post-Caregiver Hassles Scale (Kinney & Stephens) responses was not significant all of the 42 questions. None of the five categories of questions (related to daily living skills, cognitive status, behavior, and support network) reached significance. The alpha level was set at .01 for all statistics analyzed.

Research Question 2: Will communication counseling intervention have a significant effect on reports of caregiving hassles by professional caregivers’ of persons with DAT?
To analyze this question, paired t-test comparisons were made of subjects’ pre- and post-intervention scores for items with “yes” responses on the pre-intervention Caregiver Hassles Scale (Kinney & Stephens, 1989). The t-test analysis determined that the mean change, reported in Table 1 (Appendix K), between pre- and post-Caregiver Hassles Scale (Kinney & Stephens) responses were not significant for 41 of the 42 items. Question 32 was significant for 12 professional caregivers ($t = -3.32, p < 0.0069$) and indicated a decrease in hassles related to care recipients repetitive questioning. None of the five categories of questions were significant.

Research Question 3: Is there a significant difference between family and professional caregivers’ reports of caregiving hassles?

This question was analyzed using independent samples t-tests to compare group differences in improvement on pre- and post-intervention scores for items with “yes” responses on the pre-intervention Caregiver Hassles Scale (Kinney & Stephens, 1989). The t-test analysis determined that the mean change, reported in Table 2 (Appendix L), between family and professional caregivers responses were not significant for 34 of the 42 questions. Question 8 is related to assisting care recipients with toileting. Professional caregivers reported a greater decrease in hassle related to this item than family members. The mean change between groups was also significant for (a) question 8 ($t (10) = 5.16, p = 0.0004$), (b) question 18 ($t (9) = -5.43, p = 0.0004$), and (c) question 28 ($t (7) = 5.00, p = 0.0016$).

Research Question 4: Will communication counseling intervention have a significant effect on perceptions of communication problems of family caregivers of persons with DAT?
This question was analyzed using paired t-tests to compare subjects’ pre- and post-intervention scores on the Communication Perceptions Questionnaire. The t-test analyses of responses to individual questions on the questionnaire, reported in Table 3 (Appendix M), did not determine any significant change in family caregivers’ reports of communication problems with their loved ones with DAT.

**Research Question 5:** Will communication counseling intervention have a significant effect on perceptions of communication problems of professional caregivers of persons with DAT?

This question was analyzed using paired t-tests to compare subjects’ pre- and post-intervention scores on the Communication Perceptions Questionnaire. The t-test analyses of responses to individual questions on the questionnaire, reported in Table 3 (Appendix M), did not determine any significant changes in professional caregiver’s reports of communication problems with their loved ones with DAT.

**Research Question 6:** Is there a significant difference between family and professional caregivers’ perceptions of communication problems?

This question was analyzed using independent samples t-tests to compare group differences in improvement on pre- and post-intervention scores on the Communication Perceptions Questionnaire. The t-test analyses of family versus professional caregiver questionnaire pre-post intervention responses, reported in Table 4 (Appendix N), did not determine any significant differences in reports of care recipient communication problems.

**Research Question 7:** Will communication counseling intervention have a significant effect on knowledge of communication strategies of family caregivers of persons with DAT?
In analyzing this question, paired t-test comparisons were made of pre- and post-intervention scores on the Knowledge Survey. Table 5 presents the means and standard deviations for each subject groups’ pre- and post-intervention survey scores. Table 6 presents the means and standard deviations for within group differences.

Table 5

*Knowledge Survey Means and Standard Deviations*

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre-Intervention Mean</th>
<th>Pre-intervention SD</th>
<th>Post-Intervention Mean</th>
<th>Post-intervention SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family CG (N = 6)</td>
<td>2.5000000</td>
<td>1.0206370</td>
<td>7.8333000</td>
<td>3.1979368</td>
</tr>
<tr>
<td>Professional CG (N = 13)</td>
<td>3.5385000</td>
<td>0.9814275</td>
<td>7.9231000</td>
<td>2.1974758</td>
</tr>
</tbody>
</table>

Table 6

*Knowledge Survey Within Group Differences*

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean Change</th>
<th>SD</th>
<th>T</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family CG (N = 6)</td>
<td>5.3333333</td>
<td>2.4221203</td>
<td>5.39</td>
<td>0.0030</td>
</tr>
<tr>
<td>Professional CG (N = 13)</td>
<td>4.3846154</td>
<td>1.5021352</td>
<td>10.52</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

The t-test analysis determined that the mean change, reported above in table 6, between pre- and post-intervention survey scores was significant for all family caregivers (t = 5.39, p = 0.0030).

*Research Question 8: Will communication counseling intervention have a significant effect on knowledge of communication strategies of professional caregivers of persons with DAT?*
In analyzing this question, paired t-test comparisons were made of pre- and post-intervention scores on the Knowledge Survey. As seen in Table 5 there was an increase in the mean survey responses related to knowledge of communication problems associated with DAT and the FOCUSED techniques. The t-test analysis determined that the mean change, reported above, between pre- and post-intervention survey scores was significant for all professional caregivers ($t = 10.52$, $p < .0001$).

**Research Question 9: Is there a significant difference between family and professional caregivers’ knowledge of communication strategies?**

This question was analyzed using independent samples t-tests to compare group differences in improvement on pre- and post-intervention scores on the Knowledge Survey. Table 7 presents the statistical data for family versus professional caregiver differences.

Table 7

<table>
<thead>
<tr>
<th>Variable</th>
<th>df</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family vs. Professional CG Differences</td>
<td>17</td>
<td>1.06</td>
<td>0.3061</td>
</tr>
</tbody>
</table>

The t-test analysis of family versus professional caregiver questionnaire pre-post intervention survey scores, reported above, did not determine any significant differences in the amount of mean change between groups.

**Chapter Summary**

This chapter discussed the characteristics of the subject population. It also presented the statistical results of the data analysis. Research question 1 determined that there was a significant difference between pre- and post-intervention family caregivers’ reports of hassles.
related to friends not understanding caregiving responsibilities. A significant difference was found between pre- and post-intervention professional caregiver reports of hassles related to care recipients’ use of repetitive questioning and overall care recipient behavior problems. Statistical analysis of family versus professional caregiver reports of hassles revealed significant differences in responses to several questions. Research questions 4 and 5 determined that there was no significant difference in pre- versus post-intervention subjects’ reports of communication problems with persons with DAT. It was also determined that there was no significant difference in reports of communication problems between groups. A significance difference was found between pre- and post- survey scores of subjects’ knowledge of communication problems associated with DAT and their management. Finally, analysis of research question 9 was completed to determine if there was a significant difference between family and professional caregivers scores on the Knowledge Survey.
CHAPTER V

Discussion

This study investigated the effects of a group communication counseling approach to caregiver intervention for family and professional caregivers of patients with Dementia of the Alzheimer’s Type (DAT). The Caregiver Hassles Scale (Kinney & Stephens, 1989) was used to assess hassles related to caregiving duties. A questionnaire and a knowledge survey, designed by the researchers, were used to evaluate types of communication problems and knowledge of communication problems and management techniques. Pre- and post-intervention comparisons were made of subjects’ reports of caregiving hassles, perceptions of communication problems, and knowledge of communication strategies. Additionally, professional and family caregivers’ levels of improvement in caregiving hassles, reports of communication problems, and knowledge of communication strategies were compared to determine if there was a difference between these groups in terms of intervention effects.

The results of this study demonstrated that group communication counseling significantly increased professional and family caregivers’ knowledge of communication strategies for improving interactions with persons with DAT. Group communication counseling was also effective in decreasing professional caregivers’ reports of hassles related to care recipient repetitive questioning. This intervention also resulted in improved caregiver attitudes towards communication with individuals with DAT.

The effects of the FOCUSED program in the present study were not consistent with the effects of the program in a study by Ripich, Ziol, and Lee (1998) who found that the FOCUSED techniques were effective in decreasing communication hassles for family caregivers. While a significant change in professional caregivers’ level of hassles related to
care recipient repetitive questioning occurred as a result of communication counseling, this was the only significant change in caregiver hassles on the post-intervention Caregiver Hassles Scale (Kinney & Stephens, 1989). This may be due to lower levels of hassles reported on pre-intervention measures. In addition, professional caregivers were hesitant to identify hassles during counseling sessions. It is the opinion of the researcher that this was due to a belief that higher levels of hassles would reflect poorly on them professionally. This hesitation may have interfered with the accurate identification of pre- and post-intervention levels of caregiving hassles.

Some other statistically significant results were seen in pre- versus post-intervention analysis of caregiver hassles. However, upon investigation into the changes reported and the nature of the items, these results were considered anomalous. Comparisons of family and professional caregivers indicated a significant difference in pre- versus post-intervention reports of some caregiving hassles. Compared to family caregivers, professional caregivers reported a greater decrease in hassles regarding being in the care recipients’ presence. These differences may be attributed to the greater amount of time that professional caregivers spend with individuals with DAT. Compared to professional caregivers family caregivers reported a greater change in hassles related to doing care recipients’ laundry and assisting care recipients with toileting. It should be considered that family members were no longer responsible for these caregiving duties as a result of care recipients’ residence in the assisted living center.

Trends were noted in reports of hassles in both family and professional caregiving groups. Levels of hassle related to caregiving responsibilities were rated on the Caregiver Hassles Scale (Kinney & Stephens, 1989) using a Likert scale of 1 to 4 (1 = not at all and 4 =
All family caregivers reported that care recipients losing things was a hassle on both pre- and post-intervention measures. The pre-intervention mean for this item was 3. There was no mean change on post-intervention measures for this item. Some family caregivers (83%) reported that lack of understanding about caregiving by family members was a hassle. There was a post-intervention mean increase in the level of hassle reported for this item from 2 to 3. This increase may be the result of increased awareness of problems with family support after discussion with other caregivers. In addition, 83% of family caregivers reported hassles related to care recipient forgetfulness. The pre- and post-intervention means were 3 for this item. Care recipients being confused or not making sense was reported by 83% of family caregivers as being a hassle. No mean change (m=2) was demonstrated on this item. While there were no significant changes on these hassle items it is interesting to note that many of them were related to communication. It is the researchers’ belief that if the sample size were larger some significant change may have resulted for these items. A longer time period between pre- and post-counseling sessions may have given caregivers more time to implement the FOCUSED communication strategies and thereby decrease their hassles for some items.

Hassles reported by 92% of professional caregivers included care recipients declining mentally and yelling/swearing. Pre-intervention mean level of hassle related to care recipients mental decline was 2, while the post-intervention mean level of hassle decreased to 1.8. The level of hassle related to care recipients’ yelling/swearing remained constant with a mean of 2.0 on both pre- and post-intervention measures.

Eighty-four percent of professional caregivers cited the following as hassles: care recipients not cooperating and care recipients’ agitation. Hassles related to care recipients
not cooperating was rated at an average level of 2.0 pre-intervention and 1.6 following intervention. Pre-intervention mean level of hassle related to care recipients’ agitation was 2.3. This decreased to 1.9 on post-intervention reports.

There was no significant change in reports of communication problems by professional or family caregivers as a result of this intervention program. This lack of change may be due to their level of knowledge of communication problems prior to intervention. It also may be that communication counseling simply confirmed subjects’ initial observations and perceptions of communication changes as a result of DAT. Another possible conclusion is that long-term follow-up would have allowed subjects a greater period of time to implement communication strategies, thereby more effectively managing communication problems and changing communication perceptions.

Ripich, Wylke, and Niles (1995) found that FOCUSED communication training for CNAs was effective in improving staff-patient interactions and increasing knowledge of dementia. Their results, like those of the current study, indicated that the FOCUSED techniques were effective in increasing knowledge and improving attitudes of staff towards patients with dementia.

Results of the knowledge survey also indicated that family caregivers had an increased understanding of communication problems and strategies following communication counseling. McCallion, Toseland, and Freeman (1999) verified the current study’s results regarding increased knowledge when they found that 78% of family members of nursing home residents had improved knowledge of communication problems and problem management following communication training. Results of the current study indicated that 100% of family and professional caregivers increased their knowledge about communication
problems associated with DAT and strategies for managing with these problems following their participation in communication counseling.

The current study demonstrated that group communication counseling effected caregivers’ perceptions of communication interactions with persons with DAT. On post-intervention questionnaires more professional caregivers reported that communicating with persons with DAT was either more or about as satisfying as communicating with other people. The current study was also consistent with the findings of Ripich, Wylke, and Niles (1995) who found that CNAs trained in the FOCUSED strategies reported greater satisfaction in communication with patients with Alzheimer’s disease following communication training. Pre versus post qualitative responses on the Communication Perceptions Questionnaire demonstrated a decrease in the number of professional caregivers who found communication with patients with DAT to be less satisfying than communicating with others. Pre-intervention responses indicated that 77% of professional caregivers found communicating with patients with DAT to be less satisfying than communicating with others, 15% about as satisfying, and 8% more satisfying. Post-intervention responses indicated that only 54% of professional caregivers felt communication with DAT patients was less satisfying than communicating with other people, 31% about as satisfying, and 15% more satisfying.

Family caregivers demonstrated a change in the level of communication satisfaction with their loved ones with DAT. On the pre-intervention Communication Perceptions Questionnaire, 50% of family caregivers stated that communicating with their loved ones with DAT was less satisfying than communicating with others, 16% about as satisfying, and 33% more satisfying. On the post-intervention questionnaire, 50% of family caregivers
stated that communication was about as satisfying as with others, 33% less satisfying, and 16% more satisfying.

Subject data revealed that there were significant differences in pre and post-intervention measures of professional caregiver hassles related to care recipient repetitive questioning, and both professional and family caregiver knowledge of communication problems and their management. The results of the current study and those in prior research indicate that communication counseling would be an effective means of increasing caregiver knowledge of DAT and helping caregivers manage resulting communication difficulties.

**Conclusions**

The following conclusions about this research study were made.

1. Group communication counseling for professional caregivers of persons with DAT resulted in a decrease in reports of hassles related to care recipient repetitive questioning.
2. Group communication counseling resulted in increased professional and family caregivers’ knowledge of communication strategies and communication changes associated with DAT.
3. Group communication counseling resulted in improved professional and family caregivers’ attitudes towards communicating with persons with DAT.

**Limitations**

This research study was not without its limitations. The study’s first limitation was that it employed a relatively small sample size in comparison with the population of caregivers of persons with DAT. For this reason, the results of this study should be interpreted judiciously, keep in mind that only one environment, McKnight Terrace Assisted Living Center, was used to recruit subjects.
Another limitation to this study is the lack of a representative sample of the subject population. All but two of the subjects in this study were female. For this reason, caution should be exercised when interpreting the results of this research. In addition the two groups, professional and family caregivers, being compared were not equal in size or characteristics. All subjects had varying levels of education and training.

This study also does not provide any data about the long-term effects of communication counseling for caregivers of persons with DAT. Future research may be warranted to determine if the intervention resulted in any lasting effects on caregivers. There is also the possibility of experimenter bias, as the researcher counseled the subjects with knowledge of how they would be evaluated by the questionnaire and knowledge survey. Also, while the questionnaire and the knowledge survey were reviewed by the researcher’s thesis committee, their use in evaluating caregivers’ responses was not validated.

There were also limitations related to statistical analysis used for some of the research measures. The use of multiple t-tests in analysis of the Caregiver Hassles Scale and the quantitative data on the Communication Perceptions Questionnaire was necessary due to the lack of total scale scores for these items. However, it was a limitation of this study. It is also recommended that the following statistical measures be completed: (a) cronbach’s alpha analysis of the Knowledge Survey and the Communication Perceptions Questionnaire, (b) single t-test analysis of the average frequency of reported communication problems on the questionnaire, and (c) chi square analysis of quantitative data on the questionnaire.

An additional limitation to the research study was that it only assessed perceived changes in communication problems and written responses to questions of knowledge and
hassles. No direct observation was used to assess caregiver-care-recipient interactions or use of learned communication techniques.

*Implications for Future Research*

The majority of caregiver intervention models are based on long-term treatment or counseling directed at improving various aspects of caregiver and care-recipient quality of life. These programs require greater resources and time commitment than more short-term approaches to caregiver intervention. Through extensive review of the caregiver intervention literature, it was found that there is a small pool of research that evaluated the use of short-term programs for reducing stress and hassles related to caregiving. The results of this research study demonstrated one approach to providing effective caregiver intervention with limited resources. Future research should examine the use of other cost-effective, short-term programs that reduce stress and bother related to caregiving.

More research is also needed that compares the effectiveness of different intervention models on both professional and family caregivers. Specifically, research into the effects on professionals with varying degrees of education would be of interest. Research that examines the intervention needs of nurses aides versus licensed practical nurses and registered nurses is warranted to determine how to structure caregiver training for all levels of expertise. Further study of family caregiver intervention may be needed to address the differing needs of caregivers of persons with Alzheimer’s disease living in their homes versus those family members of patients in assisted living centers and nursing homes.

Research that employs hands-on-training in combination with group counseling should also be conducted. The use of a hands-on-training approach may ensure the appropriate use of communication skills during all interactions with patients with DAT. An additional merit
to this type of investigation would be the comparison of hands-on approaches to communication training counseling or education-based formats.

Clinical Implications

The information obtained for the research study suggested several important considerations for caregivers of persons with DAT. First, as seen in the literature review and demonstrated with the current study, caregivers of persons with dementia experience stress and frustration related to their caregiving responsibilities and breakdowns in communication. Unfortunately, caregiver intervention programs are not a standard part of treatment of Alzheimer’s disease and dementia. In addition, many caregiver intervention programs do not specifically address communication-related problems. In order to adequately care for and positively interact with persons with DAT, caregivers need to be trained to communicate in a manner that accommodates the person’s cognitive and communicative deficits. One way in which to effectively train caregivers in understanding and managing these deficit areas is through communication counseling programs.

Second, due to limited resources in today’s health care system and caregiver time constraints, caregiver communication interventions must affect positive outcomes in shorter periods of time. The information derived from the present study demonstrated that communication counseling presented in a short-term workshop was a viable model for effective caregiver intervention. It is important to remember that since the nature of DAT is progressive patients are not able to learn or retain new information or skills that may increase their cognitive and communicative abilities. Since dementia patients are not candidates for direct intervention, caregiver intervention should be employed to maintain quality of life and positive social interactions for persons with DAT.
Chapter Summary

This chapter provided discussion, conclusions, clinical implications, limitations of the present research, and areas for future research. Communication counseling was demonstrated to have a significant impact on caregiver knowledge of communication changes associated with DAT and how to manage these problems. Communication counseling was also effective in improving caregivers’ attitudes towards communication with persons with DAT. The above reasons support the need for caregiver interventions programs that specifically address techniques for improved communication and social interaction. This type of program should be a standard part of treatment for persons with dementia of the Alzheimer’s type. The limitations of the current study were presented and should be considered when interpreting the results. Further research investigating other communication counseling and caregiver intervention models may further enhance the findings of this study.


APPENDIX A

Research Study:
Assessing the Effects of Communication Counseling for Caregivers of Persons with Alzheimer's Disease

Professional Caregivers, Come Join Us February 7th & 21st

Sharon Jensen (graduate student) and Dr. Barbara Weinrich (speech-language pathologist) from the Miami University Speech and Hearing Clinic will present a two-part workshop focused on helping you understand your patients' communication problems. We will teach you effective strategies to increase positive interactions with your patients with Alzheimer's disease. This will help you communicate more effectively and decrease caregiver hassles.

The first of the two sessions will be held on Friday, February 7th from 3 - 4:15pm. The second session will be held on Friday, February 21st from 3 - 4:15pm. Both sessions will be presented at McKnight Terrace in the Community Room, 2nd floor.

Questions? Call Dr. Weinrich at (513) 423-0777 ext. 302
Research Study:
Assessing the Effects of Communication Counseling for Caregivers of Persons with Alzheimer's Disease

Family Caregivers, Come Join Us February 8th and 22nd

Sharon Jensen (graduate student) and Dr. Barbara Weinrich (speech-language pathologist) from the Miami University Speech and Hearing Clinic will present a two-part workshop focused on helping you understand your loved one’s communication problems. We will teach you effective strategies to increase positive interactions with your loved one with Alzheimer's disease. This will help you communicate more effectively and decrease caregiver hassles.

The first of the two sessions will be held on Saturday, February 8th from 1 - 2:15pm. The second session will be held on Saturday, February 22nd from 1 - 2:15pm. Both sessions will be presented at McKnight Terrace in the Community Room, 2nd floor.

Questions? Call Dr. Weinrich at (513) 423-0777 ext. 302

_____ (#) will attend  ______ will not attend

Name(s) ____________________________________________
Phone Number ____________________

Please return the lower portion of this form to Yvonne Myers at McKnight Terrace.
APPENDIX B

Title: Assessing the Effects of Communication Counseling for Caregivers of Persons with Alzheimer’s Disease

Professional Caregiver Consent Form

I, ______________________________, hereby authorize Sharon Jensen, a graduate student researcher, to analyze my questionnaire and survey results regarding caregiver hassles and communication counseling with persons with Alzheimer’s disease. The purpose of this study is to evaluate the effectiveness of group communication counseling for professional and family caregivers of persons with Dementia of the Alzheimer’s Type (DAT) who reside in an assisted living facility. This study involves attending two one-hour and 15-minute group counseling sessions on communication techniques for persons with Alzheimer’s disease. You will complete three questionnaires prior to and directly following the counseling sessions. The graduate student and a certified speech-language pathologist will provide this communication counseling. The counseling sessions will take place on Friday, February 7th and Friday, February 21st from 3 to 4:15 pm.

I have read the above information and acknowledge that this study has been explained to me and that the principle investigator has informed me of all the possible risks. I understand that I may telephone Sharon Jensen, graduate student researcher, at (937) 258-9418 or Dr. Barbara Weinrich, faculty advisor, at (513) 529-2548 should I have any additional questions. I understand that I may also call the Office for the Advancement of Scholarship and Teaching at (513) 529-3734 for questions about my rights as a participant in this study.

I understand that any information about me obtained for this study will be kept strictly confidential and that I will not be identified in any report or publication.

I understand that I am free to refuse participation in this study or to withdraw at any time.

My signature below indicates that I freely agree to participate in this investigational study.

__________________________  ________________
(Signature of Subject)         (Date)
Title: Assessing the Effects of Communication Counseling for Caregivers of Persons with Alzheimer’s Disease

Family Caregiver Consent Form

I, ______________________________, hereby authorize Sharon Jensen, a graduate student researcher, to analyze my questionnaire and survey results regarding caregiver hassles and communication counseling with persons with Alzheimer’s disease. The purpose of this study is to evaluate the effectiveness of group communication counseling for professional and family caregivers of persons with Dementia of the Alzheimer’s Type (DAT) who reside in an assisted living facility. This study involves attending two one-hour and 15-minute group counseling sessions on communication techniques for persons with Alzheimer’s disease. You will complete three questionnaires prior to and directly following the counseling sessions. The graduate student and a certified speech-language pathologist will provide this communication counseling. The counseling sessions will take place on Saturday, February 8th and Saturday, February 22nd from 1 to 2:15 pm.

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My signature below indicates that I freely agree to participate in this investigational study.

__________________________  ________________  
(Signature of Subject)  (Date)
APPENDIX C

*Caregiver Hassles Scale*


Pre-Training_________ Post-Training_______
Date:___________
Subject Code Number:_______ Gender:___ DOB:_____

Hassles are irritants – things that annoy or bother you; they can make you upset or angry. Some hassles occur on a fairly regular basis and others are relatively rare. Some have only a slight effect, whereas others have a strong effect.

This questionnaire lists things that can be hassles in day-to-day caregiving or interactions. You will find that during the past week some of these things have been a hassle whereas others have not.

**Note: Professional caregivers should respond to each individual item by considering their most challenging circumstance with a current patient.**

For each individual item, indicate whether the event occurred in the recent past by checking “Yes” or “No.” If you check “No”, go to the next item. If you check “Yes”, indicate how much of a hassle it has been for you by circling the appropriate number. If this question is not applicable, circle “N/A.”

*(1 being not at all a hassle to 4 being a great deal of hassle)*

*(Note: “care recipient” = person with Alzheimer’s Disease)*

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<thead>
<tr>
<th></th>
<th>BEH</th>
<th>Care recipient criticizing/complaining</th>
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<td></td>
<td>N/A</td>
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<td>not at all</td>
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<tr>
<th></th>
<th>COG</th>
<th>Care recipient declining mentally</th>
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<td>not at all</td>
<td>great deal</td>
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</table>
3. BADL  Assisting care recipient with walking

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal

4. IADL  Extra expenses due to caregiving

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal

5. SN    Friends not showing understanding about caregiving

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal

6. BEH   Care recipient losing things

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal

7. COG   Undesirable changes in care recipient’s personality

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal

8. BADL  Assisting with care recipient’s toileting

   N/A  ___ No  ___ Yes
   1     2     3     4
   not at all  great deal
9. IADL  Transporting care recipient to doctor/other places

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not at all  great deal

10. BEH  Conflicts between care recipient and family

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not at all  great deal

11. COG  Care recipient not showing interest in things

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12. BADL  Bathing care recipient

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not at all  great deal

13. SN  Family not showing understanding about caregiving

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not at all  great deal

14. BEH  Care recipient yelling/swearing

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15. BEH  Care recipient not cooperating

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16. COG  Care recipient’s forgetfulness

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17. BADL Assisting care recipient with exercises/therapy

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18. IADL Doing care recipient’s laundry

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19. BEH  Care recipient leaving tasks uncompleted

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20. COG  Care recipient being confused/not making sense

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21. BADL  Lifting or transferring care recipient

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not at all great deal

22. SN  Not receiving caregiving help from friends

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23. BEH  Care recipient frowning/scowling

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24. COG  Care recipient living in past

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25. BADL  Helping care recipient eat

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not at all great deal

26. IADL  Picking up after care recipient

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not at all great deal
27. **BEH**  Care recipient being verbally inconsiderate; not respecting other’s feelings

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28. **BEH**  Being in care recipient’s presence

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29. **COG**  Care recipient talking about/seeing things that aren’t real

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30. **BADL**  Dressing care recipient

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31. **SN**  Not receiving caregiving help from family

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32. **BEH**  Care recipient asking repetitive questions

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33. COG  Care recipient not recognizing familiar people

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34. IADL  Giving medications to care recipient

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<td>not at all</td>
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35. IADL  Preparing meals for care recipient

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<td>not at all</td>
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36. BEH  Care recipient wandering off

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<td>not at all</td>
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37. COG  Care recipient’s agitation

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38. BADL  Assisting care recipient with health aids (e.g., dentures, braces)

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<td>not at all</td>
<td>great deal</td>
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39. IADL  Care recipient requiring day supervision

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<td>not at all</td>
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40. SN  Leaving care recipient with others at home

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41. BEH  Care recipient hiding things

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42. IADL  Care recipient requiring night supervision

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BADL  =  hassle assisting with basic ADL.
IADL  =  hassle assisting with instrumental ADL.
COG   =  hassle with care recipient’s cognitive status.
BEH   =  hassle with care recipient’s behavior.
SN    =  hassle with caregiver’s support network
APPENDIX D

Communication Perceptions Questionnaire
For Professional Caregivers

Pre-Training_________ Post-Training_______
Date:_________
Subject Code Number:_____ Gender:___ DOB:_____

1. How many years ________, months ________ have you been working with patients who have Dementia of the Alzheimer’s Type (DAT)?

2. What is the highest degree or certification that you hold? Please specify specialty area.

3. What are your job responsibilities?

4. Do you feel that there are problems or breakdowns in communication with your current patients with DAT?

   a) If yes, how often do these problems or breakdowns occur? (Circle One)

      daily             weekly             monthly             rarely

5. How many current patients would you estimate have a problem communicating?
For the following items, please bring to mind your most challenging patient on which to base your answers. Please circle one response.

6. I find communicating with this patient with Alzheimer’s disease:
   A. About as satisfying as communicating with other people
   B. Less satisfying than communicating with other people
   C. More satisfying than communicating with other people

7. When I talk with this patient with Alzheimer’s disease, I sometimes feel that:
   A. He or she is generally trying to communicate, but is confused
   B. He or she generally does not want to communicate
   C. He or she is inconsistent about wanting to communicate

8. I find that this patient with Alzheimer’s disease for whom I care is:
   A. Depressed all the time
   B. Depressed some of the time
   C. Not depressed

9. I find that caring this patient with Alzheimer’s disease is:
   A. Easier when I understand why the person communicates the way he or she does
   B. More difficult when I understand why the person communicates the way he or she does
   C. The same when I understand why the person communicates the way he or she does
For questions 10 – 12 base your responses on your current caseload. For the following items, use a rating scale of 1 to 5: 1 = never occurs, 2 = occurs rarely, 3 = sometimes occurs, 4 = occurs frequently, 5 = always occurs.

10. I feel embarrassed or uncomfortable by my patients’ communication problems and/or lack of social appropriateness:

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11. I feel angered or frustrated by communication breakdowns with my patients:

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12. What types of communication problems are you and your patients experiencing?

a) Your patients make infrequent eye contact

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b) Your patients are unable to maintain a conversational topic

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c) Your patients do not initiate conversation with you or others

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d) Your patients are unsociable and ignore people

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e) Your patients talk mostly or only about things from the past

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f) Your patients do not appear interested in anything or are unresponsive

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g) Your patients are verbally disrespectful of you and others

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h) Your patients talk about things that are not real

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i) Your patients repeatedly ask the same questions

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j) Your patients frequently use words or phrases inappropriately

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k) Your patients yell or use inappropriate language frequently

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l) Your patients cannot remember names or events
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

m) Your patients cannot change topics easily and get lost when you change the subject
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

n) You have difficulty getting your patients’ attention and/or interest
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

o) You have difficulty phrasing questions and statements so that your patients understand
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

p) You have difficulty orienting your patients to the present situation
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

q) You have difficulty introducing your patients to a new conversational topic
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always

r) You have support and/or assistance from your coworkers in regards to your caregiving duties
   1  2  3  4  5
   Never  Rarely  Sometimes  Frequently  Always
Communication Perceptions Questionnaire
For Family Caregivers

Pre-Training Post-Training
Date:]
Subject Code Number: Gender: DOB:
Care Recipient Gender: DOB:

1. How many years , months has your loved one had Dementia of the Alzheimer’s Type (DAT)?

2. What is the highest degree or certification that you hold? Please specify specialty area.

3. Do you feel that there are problems or breakdowns in communication with your loved one?

   a) If yes, how often do these problems or breakdowns occur? (Circle One)

      daily weekly monthly rarely

4. Since your loved one’s diagnosis, how long have you been experiencing these communication problems?

   Please circle one response.

5. I find communicating with my loved one with Alzheimer’s disease:

   A. About as satisfying as communicating with other people

   B. Less satisfying than communicating with other people

   C. More satisfying than communicating with other people
6. When I talk with my loved one with Alzheimer’s disease, I sometimes feel that:

A. He or she is generally trying to communicate, but is confused

B. He or she generally does not want to communicate

C. He or she is inconsistent about wanting to communicate

7. I find that the person with Alzheimer’s disease for whom I care is:

A. Depressed all the time

B. Depressed some of the time

C. Not depressed

8. I find that caring for someone with Alzheimer’s disease is:

A. Easier when I understand why the person communicates the way he or she does

B. More difficult when I understand why the person communicates the way he or she does

C. The same when I understand why the person communicates the way he or she does

For the following items, use a rating scale of 1 to 5: 1 = never occurs, 2 = occurs rarely, 3 = sometimes occurs, 4 = occurs frequently, 5 = always occurs.

9. I feel embarrassed or uncomfortable by my loved one’s communication problems and/or lack of social appropriateness:

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10. I feel angered or frustrated by communication breakdowns with my loved one:

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11. What types of communication problems are you and your loved one experiencing?

a) Your loved one makes infrequent eye contact

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b) Your loved one is unable to maintain a conversational topic

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c) Your loved one does not initiate conversation with you or others

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e) Your loved one talks mostly or only about things from the past

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f) Your loved one does not appear interested in anything or is unresponsive

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h) Your loved one talks about things that are not real

1 2 3 4 5
Never Rarely Sometimes Frequently Always

i) Your loved one repeatedly asks the same questions

1 2 3 4 5
Never Rarely Sometimes Frequently Always

j) Your loved one frequently uses words or phrases inappropriately

1 2 3 4 5
Never Rarely Sometimes Frequently Always

k) Your loved one yells or uses inappropriate language frequently

1 2 3 4 5
Never Rarely Sometimes Frequently Always

l) Your loved one cannot remember names or events

1 2 3 4 5
Never Rarely Sometimes Frequently Always

m) Your loved one cannot change topics easily and gets lost when you change the subject

1 2 3 4 5
Never Rarely Sometimes Frequently Always

n) You have difficulty getting your loved one’s attention and/or interest

1 2 3 4 5
Never Rarely Sometimes Frequently Always
o) You have difficulty phrasing questions and statements so that your loved one understands

1  2  3  4  5
Never  Rarely  Sometimes  Frequently  Always

p) You have difficulty orienting your loved one to the present situation

1  2  3  4  5
Never  Rarely  Sometimes  Frequently  Always

q) You have difficulty introducing your loved one to a new conversational topic

1  2  3  4  5
Never  Rarely  Sometimes  Frequently  Always

r) You have support and/or assistance from your friends/family in regards to your caregiving duties

1  2  3  4  5
Never  Rarely  Sometimes  Frequently  Always
APPENDIX E

Communication Counseling Knowledge Survey

Pre-Training ___________  Post-Training ___________
Date:___________
Subject Code Number:_____  Gender:___  DOB:_____
Care Recipient Gender (family caregivers only):___________  DOB:_________

1. How many stages of Alzheimer’s disease are there?
   A. Two
   
   B. Three
   
   C. Four
   
   D. Not sure

2. In which stage is word finding a problem?
   A. First stage
   
   B. Last stage
   
   C. All stages
   
   D. Not sure

3. Nonverbal messages can help the person with Alzheimer’s disease understand what you are saying.
   True  False  Not Sure

4. In the FOCUSED approach, orienting to topic is the responsibility of the person with Alzheimer’s disease.
   True  False  Not Sure
5. The FOCUSED strategies may be applied to a person with Alzheimer’s disease at all stages of the disease.

   True  False  Not Sure

6. The “U” in FOCUSED stands for “unsticking,” which means to:

   A. Supply the word the person with Alzheimer’s disease is trying to say so he or she will not keep searching for it
   B. Keep talking without any pauses
   C. Encourage the person with Alzheimer’s disease to move on to a new topic
   D. Not sure

7. At what stage does a person with Alzheimer’s disease make up words or use jargon?

   A. Stage I
   B. Stage II
   C. Stage III
   D. Not sure

8. Which of the following is not one of the “exchange” strategies

   A. Using simple comments to keep conversation going
   B. Providing some clues as to what the person with AD should say in response
   C. Ask “test” questions
   D. Not sure
9. What types of questions are recommended according to the “structure” technique?
   A. Closed-choice questions, e.g., “Do you want coffee or tea?”
   B. Open ended questions, e.g., “What do you want to drink?”
   C. Yes/no questions, e.g., “Do you want coffee?”
   D. A and C

10. At what stage does the person with Alzheimer’s disease rarely correct his/her mistakes?
    A. Stage I
    B. Stage II
    C. Stage III
    D. Not sure
APPENDIX F

Caregiver Communication Counseling Session One

Introduction
I want to thank you all for coming. As you know from the flyer, you are participating in a research study to examine the effects of caregiver communication counseling on persons with Alzheimer’s disease and dementia. In order to be able to accurately determine the effects of today’s workshop, it is very important that everyone attend both sessions. I think that you will find that the second session provides more specific information about how to use the communication techniques that we will learn today. It will also allow you to ask questions about specific communication problems that you may be experiencing with your loved one/patient with Alzheimer’s.

Today, we are going to begin to discuss techniques for creating positive communicative interactions with your loved ones/patients with Alzheimer’s disease. We will begin with a brief discussion of the characteristic communication problems of people with Alzheimer’s disease and what you are seeing in your loved ones/patients. Then we will begin to learn and discuss specific techniques for improving communication and social interactions with your loved one/patient. The purpose of this workshop is to be informative as well as interactive. So, we want to keep it informal. Please feel free to ask questions at any time.

Characteristics of Communication Problems in Alzheimer’s Disease
With Alzheimer’s disease, we see a progressive decline in a person’s functioning with semantics (vocabulary and word meaning) and pragmatics (appropriate use of language) that are impaired early. Syntax (word order and sentence structure) and phonology (how we combine sounds to create meaning) become impaired later in the disease.

Persons with Alzheimer’s disease may show problems with speech production (the spoken phase of language) late in the disease. Very late in the disease a person may become totally unable to speak.

Persons with Alzheimer’s disease have impaired memory. Forgetfulness begins very early in Alzheimer’s disease and is worse for recent events as compared to events in the distant past. They have difficulty with both language and thinking tasks. Persons with Alzheimer’s disease exhibit across-the-board impairment in mental functioning. Not only is communicating through language a problem, but the basic reasoning behind the person’s original ideas is impaired.

*Can you tell me what types of communication changes you are typically seeing in your loved ones/patients communication?*

*How do you typically respond to these communication changes?*
Strategies for Improved Communication: the FOCUSED techniques

The FOCUSED program was designed to help people with Alzheimer’s disease maintain their communication skills for as long as possible. These strategies may also contribute to improved self-esteem for the person with Alzheimer’s disease. Communicating with a person with Alzheimer’s disease can be challenging and frustrating, but the FOCUSED strategies can help create supportive and effective interactions with your loved ones/patients.

FOCUSED is an acronym with each of the seven letters standing for one of the seven communication techniques of the program. Each of the techniques is designed to increase the effectiveness of interactions with people who have Alzheimer’s disease. By using all seven of these techniques each time you interact with a person with Alzheimer’s disease, you will help the person communicate as well as possible in all stages of the disease.

As we discuss the seven key words of the FOCUSED program, think about your own experiences and determine whether you have used any of these techniques. Also, as I say them repeat each of the key words to help the words stick in your memory.

*After reading each key word in the FOCUSED acronym ask the group what they think is the meaning of each key word. Respond to correct and incorrect answers with “Good idea, we will see if that is what the key word means in this program.”*

(FACE)

Now that we have learned the key words associated with the FOCUSED acronym, remembering what they stand for will be easy. You may refer to your handout to help you remember and practice the techniques associated with these key words. We will discuss each of the FOCUSED points individually and do some practice exercises to demonstrate the importance of these techniques in maintaining communication.

The first key word FACE stands for **face the person**. (poster # 2)

The purpose of this point is to attract and keep the attention of the person with Alzheimer’s disease. Begin by **facing the person directly**. This will gently force your loved one/patient to look at you, **call the person’s name**, **touch the person lightly on the arm**, or
**take his/her hand.** As you begin to speak, and throughout your conversation, **maintain eye contact.** Eye contact is a critical aspect of communication. Be sure the light is shining on your face. If you are in front of a window, the light behind you may make it hard for the person to see your face. If the person is sitting or lying down, be sure your face can be seen at a comfortable angle.

**F – FACE**
- Face the person with Alzheimer’s disease directly.
- Call his or her name.
- Touch the person.
- Gain and maintain eye contact.

Does anyone use this strategy when they are communicating with their loved one/patient with Alzheimer’s disease?

**Why do you think that this technique may be beneficial to your loved ones/patients with Alzheimer’s disease?**

The second key word **ORIENT** stands for **orient to the topic.** (poster # 3)

The O in FOCUSED refers to helping the person with Alzheimer’s disease orient him/herself to the topic of the conversation.

One strategy used to orient to the person is **repetition.** Another is to **use nouns and names.** **Repeat words,** especially key nouns, often. Remember that nouns are words for people, places, and things, such as “Eddie,” “Cleveland,” and “table.” The topic of a sentence is typically a noun, so keep in mind who or what you are talking about and repeat that word often. For example, instead of saying, “So your brother and sister are coming Sunday. They are going to take you out,” say, “BOB, your brother and sister, George and Shirley are coming to take you out to dinner.” Repeat names frequently.

You may **repeat whole sentences** and questions as well. If the person with Alzheimer’s disease seems not to understand what you are saying or asking, simply repeat what you just said. You may need to repeat it more than once.

Or you may **rephrase statements** and questions by slightly changing the wording. For example, instead of saying, “Your friend is here. He just came in the door,” it would be better to say, “Your friend, Bob, is here. Bob, your friend is here.” After the person is oriented to one fact, then you can add another bit of information. For example, once the person with Alzheimer’s disease is oriented to the fact that his friend is present, say another sentence associated with his friend, such as “Your friend, Bob, is here. Your friend, Bob, has cookies for you.”

**O – ORIENT**
Orient the person with Alzheimer’s disease to the topic by repeating key words several times.
• Repeat and rephrase sentences.
• Use nouns and specific names.

Do you find that your loved ones/patients with Alzheimer’s disease requires a lot of repetition and extra time to process information?

How do you orient them to the situation at hand?

“C” stands for continue as in continue the topic. (poster # 4)

Abrupt topic changes can confuse and disorient the listener in any communicative situation. Have you ever talked to someone who kept going off on tangents and or interrupting the course of your conversation? It can be downright irritating. For people with Alzheimer’s disease, these topic shifts can be very disorienting and discouraging. Your loved one/patient needs continuity, or smoothness, in their conversations to keep them on target.

One strategy to increase continuity includes staying on the same topic of conversation. If you begin talking about lunch, continue talking about lunch. Restate the topic throughout the conversation, so that if the person with Alzheimer’s disease forgets the topic, he or she can be reminded and can participate in the conversation again.

Sometimes you will need to change the topic in conversation. In this case, signal the change in topic. Be sure to face the person and orient him or her to the new topic. Use nonverbal gestures to show you are changing the topic. You could hold up one hand in a “stop” gesture, hold up one finger, or let some silent time pass. (Model these as you describe them.) Sometimes the person’s poor memory will work to your advantage. Simply withholding any further communication may cause the person to forget what the prior situation or topic was. This makes it easier to begin a new topic and might be the best way to do so. It keeps the person from becoming confused or disorientated.

C – CONTINUE
• Continue the same topic of conversation for as long as possible.
• Restate the topic throughout the conversation
• Use gestures to indicate to the person with Alzheimer’s disease that you are starting a new topic.

What type of nonverbal cues do you use when speaking to your loved ones/patients with Alzheimer’s disease?

“U” stands for Unstick as in unstick the communication blocks. (poster # 5)

“Unsticking” refers to helping people with Alzheimer’s disease overcome communication blocks. As the disease progresses, vocabulary shrinks. When the person with Alzheimer’s disease cannot remember the word he/she wants to use, he/she often will
substitute an inappropriate word or become silent. These are communication blocks. It is important to remember that these behaviors reflect the person’s problems with memory or shrinking vocabulary. The person is trying to communicate, in spite of these limitations.

Frequently, it will be easy for you to suggest an intended word for your loved one/patient. We do this in everyday conversation all the time. A technique that will not damage your loved one’s/patient’s self-esteem is to ask questions in a natural flow in order to clarify what the person is trying to say. We also do this in everyday conversations with our friends. Try asking, “Do you mean your son?” when your loved one/patient says his father came to visit him. Also, try just repeating the sentence using the correct word. “Oh, your son came to visit you.” If your loved one/patient with Alzheimer’s disease seems to be searching for a word, suggesting the word you think he/she is searching for is beneficial. Again, knowledge of the person’s background will help you use these techniques more effectively.

By helping your loved one/patient unstick from a communication block, you keep conversation going smoothly and naturally. Simply telling the person that he/she is wrong will cause frustration and probably bring the interaction to a close.

U – UNSTICK
• Help the person with Alzheimer’s disease become “unstuck” when he or she uses a word incorrectly by suggesting the intended word.
• Repeat the sentence the person said using the correct word
• Ask, “do you mean…?”

How do you think your knowledge of your loved one’s/patient’s past experiences and shared information will help you in unsticking communication blocks?

The key word structure stands for structure questions. (poster # 6)

“How do you think your knowledge of your loved one’s/patient’s past experiences and shared information will help you in unsticking communication blocks?”

“Structure” in the FOCUSED program refers to how you form the questions that you ask. It is better to offer specific choices (called closed-choice or forced-choice questions) when asking a question, rather than expecting the person with Alzheimer’s disease to come up with his/her own choices. Think of how much simpler it is for the person with Alzheimer’s disease to recognize one or two words than to form his/her own response. It is easier to answer the question, “Do you want coffee or tea?” than to answer the open-ended question, “What do you want to drink?”

Asking an open-ended question requires the person with Alzheimer’s disease to process a lot of information he or she may not be capable of processing. The person must understand the word “drink,” remember all the words in his or her memory categorized as drinks, decide which one is best, and then produce that word. If you give the person two choices, he or she needs only to recognize one word and repeat it. Again, this strategy keeps the interaction moving along.
You can also structure questions by asking yes/no questions rather than open-ended ones. Whenever you ask a question, be sure to allow the person plenty of time to process the question and respond. Remember to repeat or rephrase the question if necessary.

S – STRUCTURE
• Structure your questions so that the person with Alzheimer’s disease will be able to recognize and repeat a choice.
• Provide two simple choices at a time.
• Use yes/no questions.

Does anyone use this strategy with his or her loved one/patient with Alzheimer’s disease? Is it effective?

Will this strategy be easy to incorporate into your interactions with your loved ones/patients with Alzheimer’s disease?

The key word exchange stands for exchange conversation. (poster # 7)

Exchange is the basis of communication. Communication is an exchange of ideas, needs, and feelings between two or more people. The idea behind this strategy is to initiate and maintain a conversation for as long as is natural and possible. This exchange helps maintain the person with Alzheimer’s sense of belonging and self-worth. And, of course, it may increase your own self-esteem. Because you will be able to interact successfully with your loved one/patient with Alzheimer’s disease despite his or her difficulties with communication.

One technique that you can use to keep the exchange going is to use simple comments like the ones we use in everyday conversation: “Oh,” “Uh-huh,” “That’s great!” Use short, pleasant questions, just as you would when talking to a friend or acquaintance. You do not need to ask questions that put the person with Alzheimer’s disease on the spot, or “test” his or her abilities. You have heard those kinds of questions before. “What day is today?” is one example. This question is not meant to initiate conversation, but to test. Do not ask test questions.

If you see that your loved one/patient with Alzheimer’s disease is having processing difficulties or is becoming frustrated when trying to answer a question, provide some clues as to what he or she could say in response. You can supply the missing pieces. For example, if you say, “What do you think of this weather?” and the person with Alzheimer’s disease looks out the window and then back at you without saying anything, you might say, “It’s really raining hard.” This tells the person that it is raining; he or she can then use that knowledge to continue the conversation. Keep in mind that by looking out the window, the person with Alzheimer’s disease is responding. Consider this an attempt to keep the conversational ball rolling.

E – EXCHANGE
Keep up the normal exchange of ideas we use in everyday conversation.
Keep conversations going with comments such as, “oh, how nice,” or “that’s great.”
Do not ask “test” questions.
Give the person with Alzheimer’s disease clues about how to answer your questions.

*How might you feel if someone asked you “test” questions?*

*How do you think your loved one/patient might feel?*

“D” stands for direct as in **use direct statements.** (poster # 8)

“Direct” refers to the types of words and sentences we use in conversation. The words and sentences we use should be **short, simple, direct and to the point.** Try to **put the subject** (the person doing the action) **of the sentence first:** Who did what to whom. For example, instead of saying, “These flowers were sent by your sister,” say, “Your sister, Marie, sent these flowers.” **Use proper names** (the actual name of the person or place) as much as possible. **Stay away from pronouns** as much as possible. Pronouns such as “your,” “he,” “she,” “it,” “him,” and “their” can be confusing to the person with Alzheimer’s disease and they may be unable to remember what or who you are talking about. This also provides repetition that is helpful to your loved one/patient with Alzheimer’s disease.

Direct communication also means saying something in as many different ways as possible. The person with Alzheimer’s disease will be more likely to understand if he or she has more ways to take in information than just through hearing words. Only the ear picks up what we say, but the eyes can see a **gesture, facial expression, pantomime, pictures, or printed word.** Hand signals are very effective in adding more information to what we say. Using touch is also helpful to gain and maintain the person’s attention, as we discussed in the face the person technique. We can also **use touch** as a part of the direct technique to communicate care and concern by holding the person’s hand or hugging his or her shoulders.

**D – DIRECT**

- Keep sentences short, simple, and direct.
- Put the subject of the sentences first.
- Use and repeat nouns (name of people or things or things) rather than pronouns (he, she, it, their, and so on).
- Use hand signals, pictures, and facial expressions.

*What are some nonverbal cues that you could use to support your verbal communication with your loved ones/patients with Alzheimer’s disease?*

*How do you think touching the person with Alzheimer’s disease affects the communication interaction?*
Final Discussion Questions

Do you know someone who frequently asks your loved ones/patients with Alzheimer’s disease “test” questions? Why do you think he or she does that?

People often ask “test” questions thinking this is helpful or stimulating for the person with Alzheimer’s disease because it works their memory. Instead, it may frustrate them or reduce their self-esteem. You cannot improve the memory of persons with Alzheimer’s disease by having them answer questions or repeat information.

Which of the seven FOCUSED strategies do you think you have already been consistently using in your conversations with your loved ones/patients?

Which strategies do you think will be the easiest to incorporate into your communicative interactions? Which will require more awareness and practice?

What are your major concerns or frustrations regarding your loved ones/patients with DAT?

Summary

You did a great job of discussing each one of the strategies of the FOCUSED program. Again, you have used some of them before. Having them in a structured acronym, however, will help you consciously apply the principles that will improve your interactions with your loved ones/patients with Alzheimer’s disease.

I have given you a handout that reviews the FOCUSED strategies and has a practice exercise for you to complete. Between now and the next session, you may want to review and practice using some of the information you have learned today. Before our next session, use each of the FOCUSED strategies during conversations with your loved ones/patients with Alzheimer’s disease. Make notes in your handout about each of the strategies that you used and how effective it was. Please see page three of your handout. Write a brief comment about the effect of each technique, such as “good” or “able to continue conversation.”

During the next session we will discuss more specific way to deal with problems in communication with your loved ones/patients with Alzheimer’s disease. We will address the various communication problems seen at each stage of the disease and appropriate communication goals for each stage. There will also be an opportunity for you to ask questions about specific communication and interaction problems that you are experiencing.

Do you have any questions about what we have discussed today?
APPENDIX G

The FOCUSED Techniques

FOCUSED Communication Strategies

The FOCUSED program was designed by Dr. Danielle Ripich and Dr. May Wylke of Case Western Reserve University in Cleveland, Ohio. The purpose of this program is to help those with Alzheimer’s Disease (AD) retain their communication skills as long as possible.

FOCUSED is an acronym, which means that each letter stands for one of seven key points. Each one of these points is a technique you can use to help people with AD maintain their communication skills. The key words are:

- F – FACE
- O – ORIENT
- C – CONTINUE
- U – UNSTICK
- S – STRUCTURE
- E – EXCHANGE
- D – DIRECT

Once you have memorized the key words associated with each letter of the FOCUSED acronym, remembering the strategies they stand for will be easy.

These are the strategies that go with the key words of the FOCUSED acronym:

F – FACE
- Face the person with AD directly.
- Call his or her name.
- Touch the person.
- Gain and maintain eye contact.

O – ORIENT
- Orient the person with AD to the topic by repeating key words several times.
- Repeat and rephrase sentences.
- Use nouns and specific names.

C – CONTINUE
- Continue the same topic of conversation for as long as possible.
- Restate the topic throughout the conversation
- Use gestures to indicate to the person with AD that you are starting a new topic.
U – UNSTICK
• Help the person with AD become “unstuck” when he or she uses a word incorrectly by suggesting the intended word.
• Repeat the sentence the person said using the correct word
• Ask, “do you mean…?”

S – STRUCTURE
• Structure your questions so that the person with AD will be able to recognize and repeat a choice.
• Provide two simple choices at a time.
• Use yes/no questions.

E – EXCHANGE
• Keep up the normal exchange of ideas we use in everyday conversation.
• Keep conversations going with comments such as, “oh, how nice,” or “that’s great.”
• Do not ask “test” questions.
• Give the person with AD clues about how to answer your questions.

D – DIRECT
• Keep sentences short, simple, and direct.
• Put the subject of the sentences first.
• Use and repeat nouns (name of people or things or things) rather than pronouns (he, she, it, their, and so on).
• Use hand signals, pictures, and facial expressions.

Summary
The FOCUSED techniques are useful in helping your loved one/patient with AD maintain their communication skills and self-esteem. Using the techniques that go with each letter of the acronym will stimulate purposeful and meaningful interactions.

Can you fill in the key words associated with each letter?

F ___________________
O ___________________
C ___________________
U ___________________
S ___________________
E ___________________
D ___________________
**Caregiver Practice Exercise**
Before the next session, use each of the FOCUSED techniques during conversations with your loved one/patient with AD. Below, make a note of each of the strategies you used and how well each one worked. Write a brief comment about the use of each technique, such as, “good,” or “able to continue conversation.”

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Used (yes or no)</th>
<th>Effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>ORIENT</td>
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<td>CONTINUE</td>
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<td>UNSTICK</td>
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<td>STRUCTURE</td>
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<tr>
<td>EXCHANGE</td>
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<tr>
<td>DIRECT</td>
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</tbody>
</table>
APPENDIX H

Caregiver Communication Counseling Session Two

Last time we discussed changes in communication as a result of Alzheimer’s disease and strategies to help deal with these changes. Specifically, we practice the FOCUSED Strategies. *(Ask caregivers to name and describe FOCUSED strategies)*

Now, let’s discuss the practice exercises from last time. *Can anyone comment on their experiences using the techniques? Which strategies were easy to use and which will take some practice? How did these techniques work for in communicating with persons with Alzheimer’s disease?*

In this session, we will discuss the communication characteristics of people with Alzheimer’s disease at different stages of the disease. While we know that Alzheimer’s disease is progressive, it is important to remember that the rate of decline is different for each person (some people may show severe signs sooner than others). There are three stages of the disease that are characterized by certain language problems. These stages are labeled *mild, moderate, and severe.* You may also have heard these stages referred to as early, middle and late stages.

People at different stages of the disease benefit from the use of different communication techniques. While the FOCUSED strategies can be used with people at all stages of Alzheimer’s disease, the person’s communication goals are different at each stage. These different communication goals require different approaches in order to promote success during communication. In this session, we will discuss specific ways you can use each different technique at different stages of the disease.

Let’s briefly review the key points of the acronym. *(Poster # 1)*

- F – FACE the person
- O – ORIENT to the topic
- C – CONTINUE the topic
- U – UNSTICK word blocks
- S – STRUCTURE questions
- E – EXCHANGE conversation
- D – DIRECT statements

**Stage I Mild Alzheimer’s Disease**

Individuals in the early stage of Alzheimer’s disease usually live in their own homes either independently or with some supervision, in the home of a family caregiver, or in an assisted-living residence center with some help in cooking, cleaning, and other activities that might pose safety hazards. People in Stage I of the disease often do not live in extended care facilities, unless they are there for some other reason, such as a physical problem like a
broken hip. I will provide only a brief overview of characteristic problems and goals of this population.

During the first stage of Alzheimer’s disease, the person’s communicative ability is only mildly impaired. The person and their family may not even be aware that there is a problem. The sounds and sentence structure of language are usually intact but semantics, or word meanings, are impaired. The person may have trouble finding and using words appropriately. They may report trouble coming up with the right word and they are very aware of this problem. Vocabulary is shrinking at this stage.

Content is usually also impaired in the mild stage of Alzheimer’s disease. The person with Alzheimer’s disease may wander from the topic or have trouble producing a series of meaningful sentences. There is also difficulty understanding new information. Often, the person’s conversation is vague and unclear.

Pragmatics, or language use, is affected early in the disease course. The person with Alzheimer’s disease may talk too long on one subject or fail to begin conversations. They may seem apathetic, or as if they don’t care about interacting. Even at this early stage the person with Alzheimer’s disease has trouble understanding humor, analogies, sarcasm, and indirect statements. A statement such as “she robbed the cradle” may be hard to understand for the person with early Alzheimer’s disease.

Stage I Communication Goals and Approaches

The goal for communication at this stage is to keep the person engaged and in conversation with others as much as possible. Help the person by maintaining communication in as normal a manner as possible and using all of the FOCUSED techniques consistently and naturally.

Discussion Questions
What language problems would you expect a person with Alzheimer’s disease to demonstrate in Stage I?

(word finding difficulty, drifting off topic, talking too much or too little, vagueness, trouble understanding humor or sarcasm)

Is anyone seeing these problems now in their loved one/patient with Alzheimer’s disease? Can anyone recall this stage in his or her loved one’s/patients’ Alzheimer’s disease?

Stage II Moderate Alzheimer’s disease

At this stage there is a sharp decrease in communicative ability. Sound structure is still intact, but syntax, or grammar, begins to break down. The person with Alzheimer’s disease has difficulty understanding complex sentences and often produces sentence fragments or grammatical errors.
Semantics is impaired. Vocabulary is noticeably diminished and people at this stage have **significant trouble with object-naming** and **finding words in conversation**. People with Alzheimer’s disease will frequently use common social phrases, such as, “I’m fine. How are you?” They can still talk, but they **express less meaning**.

Content and pragmatics are also impaired. The person with Alzheimer’s disease still knows when to talk in conversation but **may forget the topic, repeat phrases, or fail to greet others**. The person in Stage II has lost sensitivity to conversational partners. He/she will **talk about past events** of unimportant matters and **rarely corrects mistakes**.

**Stage II Communication Goal and Approaches**

The goal for communication for people at Stage II is to help them **maintain the normal style of communication interactions**. We should initiate and maintain conversations through normal turn-taking.

We can achieve this goal by concentrating on the “give-and-take” between the speaker and the listener in a conversation. Here is how to use all the FOCUSED strategies at Stage II. (Show poster #1)

**F =** **Face the person** with Alzheimer’s disease and call their name. Touch him/her to capture attention. Use eye contact to get and keep attention.

**O =** **Orient them to the topic**. Remember that you may have to greet the person with Alzheimer’s disease if he or she does not greet you. Keep the person oriented to topic by emphasizing nouns and proper names. Repeat key words and sentences frequently when you can tell that the person has not understood what you have said.

**C =** **Maintain continuity** by referring back to the topic of your conversation whenever the person with Alzheimer’s disease forgets the topic or goes off on a tangent. If you must change the topic, wait for a minute, then refocus and reorient the person. Give him or her time to process the new message. Speaking slowly will help, as will using any available memory aids. You may also use pictures, gestures, or printed words to maintain continuity.

**U =** **Unstick communication blocks**. Because the vocabulary of someone at Stage II of Alzheimer’s disease is greatly reduced, we need to provide even more help with unsticking communication blocks. Remember to supply missing words, ask clarifying questions, or repeat phrases and sentences using words the person left out, so you are sure to understand what the person is talking about.

**S =** **Structure questions**. The need to use closed-choice questions is even more critical with people at Stage II of the disease. Pairing your spoken choices with pictures will help increase the person’s comprehension and may elicit an appropriate response.

**E =** **Exchange** is the critical factor for people in Stage II. Do everything possible to keep the interaction going, from initiating the interaction to ending it. Always respond to what the
person with Alzheimer’s disease expresses. Stop the interaction when it is appropriate to do so.

D = Use **direct statements**. To initiate and keep the interaction going, talk about familiar, concrete things. Use **short, simple sentences**. This makes it easier for the person with Alzheimer’s disease to respond. To avoid confusing him or her, use only the nouns and proper names that refer to what you are talking about. Do not use any pronouns if possible.

**Discussion Questions**

Does anyone think that their loved one/patients exhibits the communication characteristics of Stage II?

What communication behaviors have you noticed that puts them in Stage II of the disease?

(failing to greet others, straying off topic or forgetting the topic completely, trouble understanding complex sentences, expressing less meaning when talking, reliance on common social phrases)

Did you use any of the FOCUSED strategies with the person with Stage II Alzheimer’s disease?

**Stage III Severe Alzheimer’s Disease**

Persons at Stage III of Alzheimer’s disease have severely impaired communication skills, both verbal and nonverbal. Even **phonology**, or sound structure, **may break down**. Sound errors are quite common. Some syntax, or grammar, is preserved, but the person speaks mostly in sentence fragments and they will not understand many sentence structures.

Semantics, are significantly impaired. Vocabulary and word finding are very poor, as is the ability to understand words. The person may simply **make up words** or produce **jargon**, meaningless strings of sounds. The content of statements may be meaningless or bizarre. Intelligible utterances are often **retellings of past events** and are characterized by many repetitions of meaningless words and phrases.

The person at this stage has very poor pragmatic skills, such as **trouble maintaining eye contact** and poor turn-taking skills. In the worst case, the person may be **mute** (unable to speak at all). People at this stage may exhibit some limited communicative interaction through the use of gestures and other nonverbal methods to get their message across. They may also produce some verbal expressions such as “huh?” or “uh-uh.”

**Stage III Communication Goal and Approaches**

The communication goal for people at Stage III of Alzheimer’s disease is simply to **encourage the person to interact**. **Use all possible channels of communication** (both verbal and nonverbal) to initiate and maintain interactions. At this stage, respond to any behavior or response the person with Alzheimer’s disease produces that suggests an attempt to communicate. A look in your direction, a smile, a head nod, a string of words directed at
you are all attempts at communication. Let’s talk about how to use the FOCUSED strategies at Stage III. (Show poster # 1)

F = As always, directly **face the person**, call his/her name, and touch him/her to gain attention. Look directly into the person’s eyes and maintain eye contact until the interaction is over.

O = **Orient** the person by pairing spoken, printed, and gestured communications (use these forms of communication at the same time so they reinforce one another). For example, you may greet the person with a wave while you say hello. Or you might show them a picture of someone that you will be talking about. Repeat important terms using verbal and nonverbal communication. Use body posture, distance between persons, and pantomime to communicate your message.

C = To **maintain continuity**, stick to one topic only. Keep one hand on the person while using the other hand for gestures or presenting pictures to support your spoken words.

U = Help the person become **unstuck from communication blocks** by modeling what you think the person is trying to say. Assume that the person with Alzheimer’s disease is stuck in his or her attempt to greet you or initiate a conversation. If you get any idea that the person is trying to communicate, respond to him or her appropriately. Again, use nonverbal methods of responding along with your spoken words.

S = **Structure questions**. Even closed-choice questions may be too difficult for the person at Stage III to understand. Always use a nonverbal support when the person needs to make a selection. If possible, show the real objects. For example, show them two containers of juice when asking them if they want orange or apple juice with their lunch.

E = **Keep up conversational exchange**. Again, you may have to initiate most interactions with persons who are severely impaired. If you see nothing that remotely appears like an attempt at communication, then you initiate communication. Even if all you get is a smile in return, you have achieved interaction.

D = **Keep statements as direct as possible**. All communication should be simple, direct, and precise. Get into the habit of pairing everything you say with some form of nonverbal assistance. Nonverbal communication is usually required when interacting with people at Stage III.

Here’s an example of common event, the person with Alzheimer’s disease is going to bed. You may include in your discussion things that precede going to bed (e.g., taking pills or changing clothes). These interactions will likely be short, possibly fleeting, but there should be many nonverbal interactions. For example, you can give them a visual and verbal choice of which pajama’s they would like to wear or showing them and a pill case and instructing them that it is time to take their pills.
Discussion Questions
What nonverbal techniques would you use that enhanced communication? Do you use any of these with your loved ones/patients?

What problems have you experienced when using various types of nonverbal communication?

Summary
We have discussed the characteristics of communication at each of the three stages of Alzheimer’s disease. We have learned how language and communication break down as the disease progresses.

Each stage—mild, moderate, and severe—requires its own communication goal and methods of approaching that goal. You have done a great job discussing the FOCUSED strategies during these two sessions. I think you will have some success in using these strategies with your loved ones/patients.

As we know, Alzheimer’s disease is a devastating disease. It robs affected people of intellectual functions and the ability to communicate through language. We cannot be sure, however, that the person with Alzheimer’s disease does not have windows of awareness. A fleeting smile, a nodding head, a glance in your direction; any of these behaviors may be considered attempts at interaction.

As caregivers, it is your job to help maintain the communication skills of people with Alzheimer’s disease for as long as possible. By doing so, you contribute to their sense of self-esteem and feeling of social belonging and lessen your frustration. Sometimes we are not sure that what we do makes a difference. It does make a difference.

By consistently using these communication strategies, you will know that you are doing your best for the person with Alzheimer’s disease. The strategies will help the person prolong and maintain his or her communication skills.

Thank you for your participation today. Do you have any questions or comments about anything we have discussed in these two sessions?
APPENDIX I

Characteristics of Communication Problems at Stage I: Mild Alzheimer’s Disease

**Phonology (sound structure):**
Used correctly.

**Syntax: (grammar and sentence structure):** Generally correct.

**Semantics (vocabulary and word meaning):**
May omit a meaningful word, usually a noun, when talking in sentences. May report trouble thinking of the right word. Vocabulary is shrinking.

**Content:**
May drift from the topic. Reduced ability to generate a series of meaningful sentences. Difficulty understanding new information. Conversation is vague.

**Pragmatics (use of language):**
Knows when to talk, but may talk too long on a subject. May be apathetic, failing to begin a conversation when it would be appropriate to do so. May have difficulty understanding humor, analogies, sarcasm, and indirect or ambiguous statements.
Stage I Communication Goal and Approaches

Communication Goal

Keep the person engaged and in contact with others.

Approaches

1. Maintain communication in as normal a manner as possible.

2. Use all of the FOCUSED techniques consistently and naturally.
Characteristics of Communication Problems at Stage II: Moderate Alzheimer’s Disease

**Phonology (sound structure):**
Used correctly.

**Syntax: (grammar and sentence structure):** Sentence fragments and grammatical errors common. May have difficulty understanding complex sentences.

**Semantics (vocabulary and word meaning):**
Vocabulary is noticeably diminished. Has word-finding problems in conversation and difficulty naming objects. Relies on common social phrases.

**Content:**
Frequently repeats ideas. Forgets topic. Talks about past events or trivia. Fewer ideas.

**Pragmatics (use of language):**
Knows when to talk. Recognizes questions. May fail to greet others. Loss of sensitivity to conversational partners. Rarely corrects mistakes.
Stage II Communication Goal and Approaches

Communication Goal

Maintain the normal style of communication interactions.

Approaches

1. Keep up the normal “give-and-take” of conversation.

2. Use all of the FOCUSED techniques to maintain turn-taking.
Characteristics of Communication Problems at Stage III: Severe Alzheimer’s Disease

**Phonology (sound structure):**
Sometimes correct. Sound errors are common.

**Syntax: (grammar and sentence structure):**
Some grammar is preserved, but sentence fragments are common. Does not understand many grammatical forms.

**Semantics (vocabulary and word meaning):**
Marked word-finding problems. Poor vocabulary. Poor word comprehension. May make up words and produce jargon.

**Content:**
Statements may be meaningless or bizarre. Generally unable to produce a sequence of related ideas. Intelligible utterances are often retellings of past events. Many repetitions of words and phrases.

**Pragmatics (use of language):**
Difficulty maintaining eye contact and conversational turns. Mutism possible.
Stage III Communication Goal and Approaches

Communication Goal

Encourage the person to interact.

Approaches

1. Use all possible channels of communication: words, gestures, facial expression, touch, pictures, printed words, and pantomime.

2. Respond to any attempt at communication, no matter how slight.

3. Use all the FOCUSED techniques to stimulate interaction.
APPENDIX J

Tips for Caregivers of Persons with Dementia of the Alzheimer’s Type: Managing Problem Behaviors and Improving Daily Living
Managing and Preventing Problem Behaviors

Wandering

Reasons for Wandering:
The person may be:

- looking for a lost item
- looking for familiar surroundings
- agitated due to medication, over stimulation, noise, or confusion
- disorientated or hallucinating
- suffering from stress

Managing Wandering Behavior
- Determine the type of wandering. Is it goal-oriented or aimless? If there is a goal, help the person meet it.
- Provide an outlet - a walk, activity or memory book
- If there are delusions or hallucinations, avoid direct confrontation. Remember what the person is seeing or hearing is real to that person. Try to call them back by calling their name and lightly touching them. Provide a reality-oriented statement (“No one is going to hurt you. I am here and I will keep you safe”).
- If wandering is common at night, try a walk around the facility or other light exercise.
- Minimize noise and distractions. Dim lighting can be calming.

Sundowning

Sundowning is a phenomenon where the person with Alzheimer’s disease becomes highly confused, agitated and/or combative in the late afternoon or evening.

Possible Reasons for Sundowning:
- Decreasing levels of light may be disorienting. Less light allows fewer clues to the person’s surroundings and may create frightening shadows.
- The person may feel that it is “time to go home.”
- Fatigue at the end of the day may increase frustration.
- The brain centers that trigger waking and sleeping cycles may be damaged by Alzheimer’s disease.
- Shift changes may occur at this time and cause confusion.
- A lack of comforting noise (i.e., talking or background music) may cause panic.
Minimizing Sundowning:
• Leave the lights on and close shades and curtains to shut out the darkness. Install a night-light and make sure there is a well-lit path to the bathroom.
• Try to reduce activity around the end of the day to avoid over stimulation.
• Reduce the person’s caffeine intake.
• Encourage afternoon naps to reduce fatigue.
• Try a soothing bath before bedtime.
• Encourage more activity earlier in the day to use up energy and reduce stress.

Rummaging, Hiding and Hoarding

Reasons for Rummaging, Hiding, and Hoarding:
• May be an attempt to regain control. People with Alzheimer’s disease have lost much of their memory, intellect, social skills and control. All that remains may be tangible possessions and because of this feeling of loss of control the person may guard possessions.
• Rummaging indicates a need of some kind, but most professionals indicate that they do not know what it is. It could be boredom or another way to control the environment.
• Rummaging is done out of confusion or fear and nothing else.

Managing Rummaging, Hiding, and Hoarding:
• Place a large, colorful sign that says “NO!” on places that you don’t want disturbed.
• Look for patterns or; if the person keeps looking for the same thing, such as a watch, give them one of their own.
• Fill a top drawer of a dresser or nightstand with things that are “rummageable” and let the person go through it.
• Label everything in the environment with words or pictures so that the person may not feel the need to rummage.
• Consider keeping the person’s closet at all times. This will help keep them from searching through it.
• Keep everyday items in view so that the person does not need to look for them.
• Try to identify favorite hiding places when looking for lost items.
General Suggestions to Help Patients with Alzheimer’s Disease

- Serve hot instant oatmeal with brown sugar at bedtime to help induce sleep.
- Have a memory book to help the person feel oriented and relaxed. It is also a great conversation piece. (Instructions for making a memory provided later in the handout).
- Play soothing background music (Mozart or other gentle classical music).
- Black toilet lids to reduce confusion.
- Soft fuzzy toys to touch and hug; the last sense to deteriorate is that of touch.
- Sponges to squeeze during baths to reduce staff scratches by patients.
- Serve each food at mealtime separately to avoid confusion.
Activities for People with Alzheimer’s Disease

**Exercising/Relaxing:**
Watering plants
Dancing or stationary exercise program (maybe a video, such as “Sweatin’ to the Oldies”)
Massage

**Household Activities:**
Sorting/folding laundry
Knitting
Preparing certain foods (cutting vegetables for a salad, baking)
Dusting or polishing furniture in his/her room
Drying dishes

**Psycho/Social Activities:**

*Listening/singing favorite songs*

Reminiscing/looking at a photo album
Pet visits (some organizations will bring pets to visit at nursing homes or assisted living centers)
Volunteer work (stuffing envelopes)
Doing a puzzle (look for a large format)
Building with legos

*Creative Visiting*

**When to Visit:**
Keep visits short and at a time when the person with Alzheimer’s disease is at his/her best. Morning or after a rest time are usually best. Set a time period rather than waiting to leave until your loved one is tired. Remember that a few short visits are generally more pleasant than one long one.

**General Suggestions for Visiting:**

* When possible, a walk outside or a visit to a local café or coffee shop can be a nice change of pace for the person with Alzheimer’s disease.

* If going out is not possible, “bring the outside in” by bringing a picnic lunch and colorful tablecloth. For a special occasion, bring decorations and a cake. It is also helpful to bring along pictures and memories from earlier picnics and special occasions.

* Attend programs and activities at the center together.

* Visit with other patients and their families.
• Bring another family member or friend if possible. Remember to include everyone in the conversation.

What to Talk About:
• Photographs and other tangible objects can stimulate memories and conversation. This is a time to share appreciation for the contributions the person made in the past. When someone is ill and feeling helpless, it is important to remind them of the times when they offered strength and support to others.

• Bring news articles, magazines and other reading materials that have a common interest. Many persons with cognitive impairments can still read news headlines and have an opinion about current events. Make sure that you discuss the topic, using questions such as “What do you think about …?” Do not test the person “Do you know the name of the President?”

• Sing songs together if the person likes music or singing. Sing songs from the person’s era or favorite songs (hymns, old standards etc…)

• Play games. Junior Scrabble, Pictionary, and simple card games can all be fun.

• Bring a light video, such as a musical or an old TV show (“I Love Lucy” or a favorite sitcom), and watch it together.

• Celebrate special events. Have a small party in the person’s room.

• Help the person decorate their room for an upcoming holiday, like St. Patrick’s Day.

• Write letters to another friend or relative.

• For women, it might be nice to paint the patient’s nails or put on make-up. For any patient a back rub or hand massage with a fragrant lotion might be enjoyable.

• If religious observance is important to the person, arrange a weekly trip to church/synagogue/mosque or request pastoral visits if these are available. Some religious services are on TV.

• Plant a potted plant or window box for the person’s room. This can be a nice activity during the winter to welcome the spring season.

• Make a memory book with the person. This will provide the person with a comforting resource even when a familiar face is not present. It will also be useful to staff caregivers for initiating conversation with the person.
How to Make A Memory Book:

1. Select a photo album with large-sized picture pages to accommodate pictures/documents of all sizes.

2. Decide if your loved one can help with choosing the visuals and writing the narrative.

3. Decide how you want to name the life stages. Here are some suggestions:
   • Original family
   • Early years (birth to adulthood)
   • Work history (childhood jobs, adult career, and on to retirement)
   • Courting and marriage
   • Spouse’s history
   • Children and children’s weddings
   • Family and friends
   • Recreation, hobbies, and interests

4. If the person has vision problems, try to choose pictures that are large enough for them to see clearly. Try and locate interesting documents (military records, marriage certificates, etc.)

5. Create a narrative for each life stage so anyone reviewing the book has enough background to understand the family and can ask appropriate questions. Place the narrative at the beginning of each section.
## Table 1

**Caregiver Hassles Scale Within Group Differences**

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Table 1 (continued)

**Caregiver Hassles Scale Within Group Differences**

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Caregiver Hassles Scale Within Group Differences

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APPENDIX L

Table 2

Caregiver Hassles Scale Family Versus Professional Between Group Differences

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## APPENDIX M

### Table 3

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*p < .01
APPENDIX N

Table 4

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