5-2012

A Family's View: The Necessity and Effects of Therapy throughout Alzheimer's Disease from the Family's Perspective

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Citation

Taylor, K. (2012). A Family's View: The Necessity and Effects of Therapy throughout Alzheimer's Disease from the Family's Perspective. *Rehabilitation, Human Resources and Communication Disorders Undergraduate Honors Theses* Retrieved from https://scholarworks.uark.edu/rhrcuht/15

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Program in Communication Disorders
Honors Thesis
Spring, 2012

Abstract

The purpose of this study is to determine what activities and/ or level of human interaction will prolong language and functionality in Alzheimer's disease in order to showcase the importance of therapy for those affected with Alzheimer's. The participants will include 50 Alzheimer's patients' family members or close friends. Twenty five of these should have a relative affected by AD and living on their own or with family, and twenty five should have a relative that lives in an assisted living facility or nursing home. Each of the living situations will represent the stage of the disease the patient is in (mild, moderate, severe). A survey developed from the literature will be used to collect the data. The surveys will be distributed to doctor's offices, community centers, assisted living facilities, and nursing homes where family members of patients can voluntarily fill out and submit the surveys anonymously. The data will be analyzed descriptively.

The Necessity and Effects of Therapy throughout Alzheimer's Disease

Alzheimer Disease is a degenerative disease of the brain that over time debilitates the person to the point where they cannot perform simple, everyday tasks. It is a horrible and sad disease that affects not only the person with the disease, but also those close to them. It is estimated that about 5.1 million Americans are Alzheimer patients with that number growing annually (Alzheimer's disease Education and Referral Center [ADEAR], 2010). Alzheimer's disease develops in stages with the symptoms and effects growing worse in each stage. In the beginning, signs include memory problems, repeat questions, and have more problems completing tasks like paying bills (ADEAR, 2010). In the moderate stage, language is affected and the patient may not recognize friends or family. They may have difficulty performing tasks with multiple steps, and can suffer from hallucinations, paranoia, and delusional thoughts (ADEAR, 2010). In the severe stage, the patient loses all communicational function and requires constant care. In this stage their body shuts down step by step until they eventually pass away (ADEAR, 2010).

Many confuse Alzheimer's with dementia; however these are two separate conditions Dementia is loss of cognitive functioning, meaning they have problems thinking, reasoning, and remembering. Alzheimer's differs because it slowly gets worse over time, prevents them from doing simple tasks, and eventually becomes the cause of their death.

There is no cure for Alzheimer's. Once the patient is diagnosed, there is no known way to completely stop the disease; however there are ways to slow the progressive loss of function. This includes medication, nutrition, and life-style changes. . One medicine designed to slow the progression of Alzheimer's is Nerve Growth Factors (NGF). These are supposedly able to exert functions throughout the body and support neuron survival and function as people age (Capsoni, Cattaneo, Covaceuszach, Spirito, Ugolini, & Vignone, 2009). There are also studies that nutrition can help preserve functioning. For example, there is evidence that foods high in Omega 3 fatty acids and Vitamin E can lower the risk and rate of Alzheimer’s (Morris, 2009). Lifestyle changes such as regular exercise has some scientific support (Briones, 2006). Alzheimer’s patients even without such evidence believe that it is important to keep their minds active by doing games such as cross word puzzles, Sudoku, and word searches. Some do a hobby that they have done their whole life. Everyday life activities have been studied as therapeutic intervention. An example of this is reminiscence therapy, which takes many forms. Damianakis, Nishihata, Smith, Baecker and Marziali (2010) designed a study that videotaped family members talking about their loved one affected by Alzheimer’s. It included the patient’s early history through all of their family members and later life. This study stimulated reminiscing to try to work the patient’s brain to remember aspects in their own life.

As can be seen, there are a number of ways that individuals, families and medical professionals seek to maintain functional living skills for those who suffer from Alzheimer's. This study seeks to determine if the beliefs about how best to maintain cognitive functioning differs for family members of patients based on the progression of the disease.

Review of the Literature

What is Alzheimer’s disease?

The disease known as Alzheimer’s (AD) is a debilitating and devastating degenerative disease whose direct cause is still unknown. It may be linked to genetics and the greatest risk for it is increasing age. While some dementia patients are later diagnosed as having Alzheimer’s, the two aging diseases are different from one another. They both include the deteriorating of cognitive abilities; however Alzheimer’s also includes the shutdown of bodily functions and organs that eventually leads to death. All aspects of a person’s life are eventually affected by Alzheimer’s. The most common and noticeable first sign of possible Alzheimer’s is problems with absorbing and maintaining new information (Cacace, 2007). Other warning signs include memory loss, problems doing everyday tasks like cooking, playing cards, and paying the bills, wandering, not able to follow directions, confusion with places and times, poor judgment, losing things, changes in mood, and language problems including difficulty finding the words to describe or form sentences. They often have organizational problems and other cognitive dysfunctions (Cacace, 2007).

Alzheimer’s is a prominent disease in the U.S. today with nearly 5.1 million people over the age of 65 being affected. This number is expected to double by the year 2030 as more is being learned about early signs, symptoms, and possible causes (Cacace, 2007). Alzheimer’s disease is classified into stages based on the severity level of the disability. These stages will be described as mild, moderate, and severe. Patients progress through the stages and eventually pass away due to the disease. Diagnosis can be seen through the quantity of neurofibrillary tangles and senile plaque formed in the brain. These can cause neurological miscommunications that manifest themselves in the symptoms of AD (Phillips & Taler, 2008). It is also suggested that hippocampus atrophy is seen before the onset of the disease (Phillips & Taler, 2008). There is no cure for Alzheimer’s disease. Once it is diagnosed, the well being and cognitive state of the patient will degenerate; however, there are ways to slow down the progression of Alzheimer’s disease. These include both medical and non medical treatments.

How Does Alzheimer's Affect Language at the Different Stages?

Alzheimer's disease is recognized as a leading cause of language impairment in elderly adults. There are three stages of progression. All aspects of language are eventually affected by AD even if not until the very late stages of the disease.

Stage I: In the mild stage of AD, the most affected aspect of language as well as the most affected throughout the progression of the disease, is pragmatics. Language use becomes difficult and often times patients with Alzheimer's may begin to isolate themselves rather than struggle to communicate. (Desai, Manepalli& Sharma, 2009). They begin to use more vague terms and do not elaborate as much. Their statements become fewer; they go into less detail as well as not focusing on main points in a conversation; and in general speak less. Their language is often described as empty. This is sometimes associated with the fact that their attention is affected by AD therefore they cannot focus to give a full and accurate description of people, places, pictures, and things. (Berrewaerts, Feyereisen, & Hupet, 2007). One reason for this decline in elaborations and statements is due to anomia. Anomia is difficulty finding words. The patient may know what he or she wants to say or what something is, but they have difficulty coming up with the word for it, if they ever do. Many times they will use gestures to try to compensate for this such as pointing to objects or using hand gestures to try to describe the word they are searching for. (Dye, Hoffmann, Irinyi, Kalman, Nemeth & Pakaski, 2010). One study however found that people affected by AD are more successful at naming artifacts rather than items of a biological nature. This means that they were better at retrieving words of artifacts like clothing items, furniture, and tools, and had more difficulty naming biological items like animals, fruits, people, etc. (Phillips & Taler, 2008). This tendency seemed to increase as anomia worsened in AD patients.

Stage II: In the moderate stage, decline in language becomes more profound, especially in the areas of semantics and pragmatics. (Forbes & Venneri, 2005). Semantics has to do with word meaning. This differs from amonia in the pragmatics aspect. Amonia, as mentioned before, was more that the patient could not find the word for the object. They know the name of things and the meaning of the word, they just can’t put that meaning and the name or label together. In semantic knowledge, the patient may not use the right word in the right place or context. They don’t associate the word with the meaning. This makes communication more difficult and confusing for the patient and the caregiver because wants and needs are not successfully communicated leading the patient to become frustrated and angry.

Both semantics and pragmatics are affected early on in the progress of AD. They have done studies where the researchers look back at peoples’ journals from when they were younger and were able to find subtle language changes years before actually being diagnosed with AD (Forbes & Venneri, 2005). One specific example is Ronald Reagan in his 1984 re-election campaign. A language expert who analyzed his speeches of that time could detect that Reagan had language alterations and a persistent decline of linguistic skills some ten years before his Alzheimer’s diagnosis (Forbes & Venneri, 2005).

Stage III: While the impact of AD on pragmatics and semantics begins early on, the severe stage of the disease affects syntax and phonology. There may be misspellings of words in earlier stages, which suggest a phonological component, but this is due more to the decline on the semantic level of not understanding the meaning of a word they may be spelling (Forbes & Venneri, 2005). Syntax and phonology are only seen to be truly affected in the very final stage. As a result, essentially all communication skills are lost at this point.

Therapies, Interaction, and Daily Living

Since there are no real cures for AD, it is important to do different therapies to try to slow the progression of the disease as well as make living as enjoyable as possible for the patient and caregiver. Depression and anxiety are common side effects of AD that may be managed with medication. This management can facilitate interactions. There are a host of other behaviors that interfere with effective social interactions. It is suggested that many symptoms of AD are coinciding with patients' wants and needs (Desai, Manepalli, & Sharma, 2009). The goal of therapy for an AD patient is to improve and prolong the quality of their daily life. The patient with Alzheimer's disease needs to have motivation and support in order to adjust to living with the disease with as little stress and anxiety as possible. The importance of family interaction and connection is a considerable factor for the patient with Alzheimer's well being and progression. As their cognitive abilities to remember the past declines, the family unit becomes the primary source of the patient's history and sense of personality (Woods, 2001). Not only is the family relied on for maintaining the patient's sense of self, but as the disease progresses, family members or primary care givers are more heavily relied on for meeting the patient's health, behavioral, and daily needs. This is especially true in the severe stage of Alzheimer's when the patient can no longer feed, bathe, or cloth themselves, can no longer monitor their safety and well being, when their hallucinations and possible agitation becomes more frequent and severe, and when their ability to communicate is no longer functional (Herrmann & Gauthier, 2008). To handle increasing debilitations and probable care giver stress, it is important for families to be educated about the helpful therapies available, what to expect as the disease progresses through each stage, and what resources are available. Resources are now made available to the public including people with Alzheimer's disease and their families. These include organizations like the Alzheimer's Disease Education and Referral Center or ADEAR, or the Alzheimer's Association. Both of these groups are founded on informing the public of symptoms and the stages, as well as offering help finding support groups or local physicians and therapy.

In the mild stage and early moderate stage of Alzheimer's, the patient may use memory games and puzzles like word searches or crossword puzzles to stimulate cognition on a day to day basis (Desai et al., 2009). Also within these first few stages, memory aids can assist in minimizing cognitive stress (Woods, 2001). These can include things like having an old personal momentum like a diary, pictures of family, or sentimental objects. This can also include simplifying the patient's environment to rid them of extraneous, unnecessary stimuli that may make taking in information harder (Woods, 2001). In terms of language use these memory aids along with written or verbal cues can be used to help the patient remember the name or label of an object or person (Woods, 2001). An AD patient's behavior can be improved with human interaction on a daily basis and different therapy techniques that require the patient to elicit speech or recall items can facilitate this. Group therapy is helpful to initiate conversation with communication partners as well as providing a support group of people to decrease stress of AD. Reminiscence therapy is used within group or independent therapy to elicit speech as well by having the patient recall past. The client is allowed to tell stories from their past. These can include memories of big events, like getting married and or becoming a parent, to times of happiness of their favorite memory, or even just talking about friends and family of past and present. It allows for them to reminisce in the events of their life while also serving the purpose of maintaining pragmatics and semantics. (Desai, Manepalli, & Sharma, 2009) Psychotherapy also has been suggested to help the patient retain their communication skills as well as their sense of self (Woods, 2001). In psychotherapy the individual affected by Alzheimer's is encouraged to communicate their feelings and stresses of the early impacts of the disease or other life events. They practice listening and facilitating communication in a non threatening one on one situation. As the disease progresses into the final stages, therapy is more aimed at managing behavioral aspects such as aggression and agitation as well as pharmacological therapies for depression, anxiety, and any health issues. These later stages are more about making the patient as comfortable as possible (Herrmann & Gauthier, 2008).

Summary and Questions of the Study

As can be seen from the literature, even in the earliest stages of AD, social interactions and communication is impacted. Some of this is due to the disease process. Literature suggests that information to families and patients can be used to improve functionality and quality of life during the early stage. A number of therapies, some of these supported by research, are commonly available to patients and families. These include cognitively engaging tasks, such as puzzling, while others focus on distance and recent memory, such as reminiscence therapy. Across these, the goal of different therapies and interactions is to maintain functional skills as long as possible. This is pivotal from the perspective of health care for the individual affected by Alzheimer's, but may not be as clear to the families of these individuals. Thus, the purpose of this study is to determine, from the family's perspective, what they believe the goal of such intervention is and how effective it is as the disease process progresses.

Questions of the study. This research seeks to answer the following two questions.

1.) In the family's perspective, are there certain therapies or amount of interaction/ communication with people and family that are believed to be more efficient at delaying the progression of Alzheimer's disease?

2.) In the family's perspective, does the need for therapy change depending if the person with Alzheimer's is in their own home, family members home, or in an out-of-home placement?

Methodology

Participants

Fifty participants were sought for this study, 25 of whom had family members or close friends with AD who are living in an assisted living or nursing home and 25 with family members or close friends of patients who live in their own home or with a family member. Race and gender was not controlled for in this study. All participants and their family member/friend will be English speaking.

Materials

A paper pencil survey, based on the literature, was devised by the researcher. This included a first section that focused on demographic information including residence of the family member/friend with AD; a second section that focused on reported language skill functionality, memory functionality, and ways that cognitive-linguistic functioning is being preserved; and a third section that allowed the participants to address their beliefs about the effectiveness of interventions.

Procedures

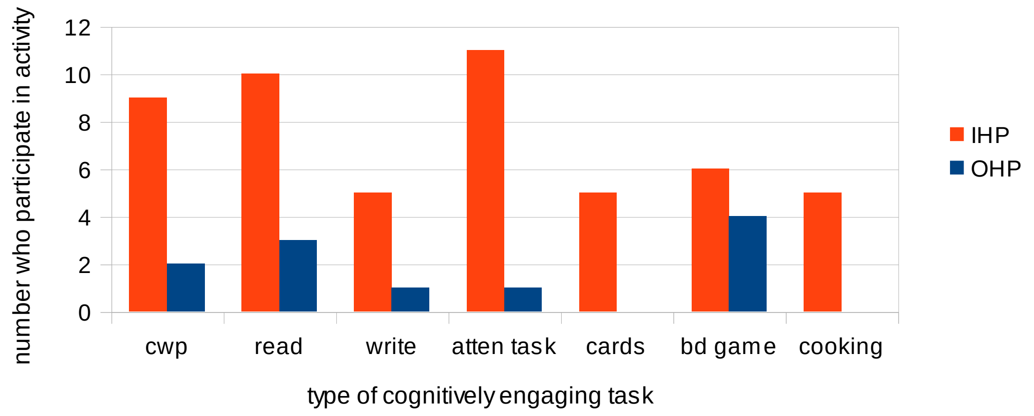
Local agencies, AD support groups, and medical practitioners were contacted and asked to make the survey available to family members of individuals with AD. Participants voluntarily and anonymously filled out the survey and returned it to the researcher in a sealed envelope. A collection box was made available for depositing the envelope at support group meetings and in doctors' offices. Surveys from these sites were collected every other day. For participants who did not want to use collection boxes, stamped and pre-addressed envelopes were made available for the return of the survey to researcher.

Results

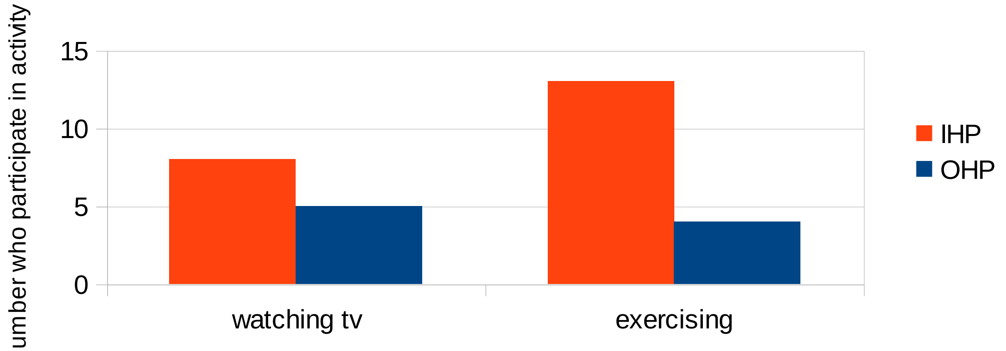
Twenty two participants completed the questionnaire. Data was collected primarily from 3 organizations: an Alzheimer's day care group at a local church, an assisted living home and also through local chapters of the Alzheimer's Association of Arkansas. Information regarding the persons with AD living arrangements was collected. Participants reported persons with AD living in various arrangements which for the purpose of data analysis in the present study were grouped in either in-home-placements (IHP) or out-of home placements (OHP). Of those respondents reporting IHP, eight participants stated their loved one lived at home with their spouse, five lived in another family member's home, one lived in their own home with an adult child and one lived in their own home with unrelated caregivers. Those persons with AD living in OHP had reported living arrangements as follows: five lived in an assisted living home and two lived in a nursing home. In the present study, placement was used as an indirect indicator of the severity of AD symptoms. It was assumed that those in IHP represent persons with AD in the earlier stages of the disease (more independent) and those in OHP will represent persons with AD who are in the later stages of the disease (more dependent). In the results to follow, frequent comparisons between IHP and OHP groups will be utilized to address the primary research questions. The first main research questions seeks to shed light on which therapies or types of interactions are most effective in delaying the progression of AD symptoms. An underlying assumption inherent in this question is that some effective therapies exist. This assumption appeared to be supported by the data as all of the 22 respondents (100%) believed that therapy was important for persons with AD at some point in time. Sixteen of the 22 (73%) reported that their loved one received some sort of treatment or therapy. Ten out of the 16 who receive therapy reported that their loved one with AD participates in some type of group therapy or support group. Of the ten in group therapy or a support group, 80% were in IHPs and 20% lived in OHPs. Pharmacological interventions to help delay Alzheimer's progression and help with aggression caused by the disease were reported by 14 of the 22. These include: 3 taking Namenda (3), 6 taking Aricept (6), 3 taking Exelon (3), and unspecified (4). Of those who take medications 28% live in OHPs, and 72% live in IHPs.

The number of hobbies or activities that persons with Alzheimer's Disease participate in were investigated in each of the settings (to reduce cumbersome phrasing the more general term “activity” will be used in place of “activities or hobbies”). Those persons with AD living in IHP reportedly engaged in 3-5 activities versus 2-3 activities for those in OHPs. Participants were asked to identify which activities that their loved one with AD participated in. The activities were classified as varying between cognitively challenging and less cognitively challenging. The cognitively challenging activities included crossword puzzles, reading, writing, card games, board games, and cooking. Data was collected demonstrating that permitted ranking activities from greatest number of participants to the least as follows: Reading (13), Attention maintenance tasks (12), crossword puzzles (11), board games (10), writing (6), card games (5), and cooking (5). The results were further broken-down to compare IHP versus OHP for these activities: Reading (10:3), attention maintenance tasks (11:1), crossword puzzles (9:2), board games (6:4), writing (5:1), card games (5:0), and cooking (5:0). (Figure 1.1). Less cognitively challenging activities that were reported included watching TV (13 people) and exercising (17 people). Subsequent comparison by IHP and OHP of these same activities were watching TV (8:5) and exercising (13:4). (Figure 1.2).

Comparison of Placement and # of People Who Participate in Variety of Cognitive Tasks (Figure 1.1)

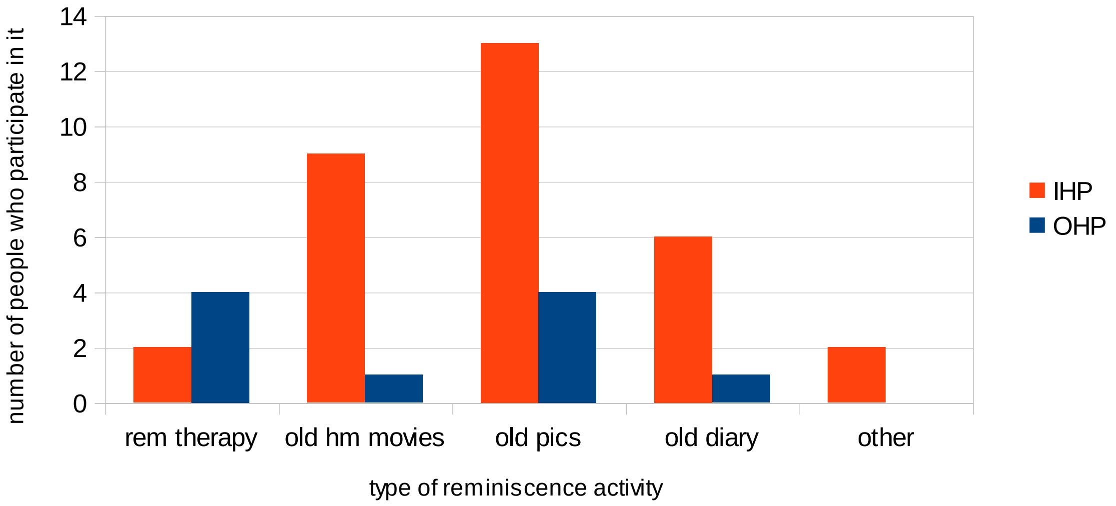


Comparison of Placement and # of People Who Participate in Simple Activities (Figure 1.2)



Another survey item sought to determine whether the respondent's loved one with AD participated in reminiscing activities. Response choices permitted respondents to select any of the following such activities: reminiscence therapy; watching old home movies; looking at old pictures; reading an old diary, or an open-ended response. The results reported, from most to least common reminiscing activities, were as follows: Looking at old pictures (17), watching old home movies (10), reading old diaries (7), and reminiscence therapy (6), and other (2). "Other"

Comparison of Placement and Reminiscence Activities Participated In (Figure 2.1)

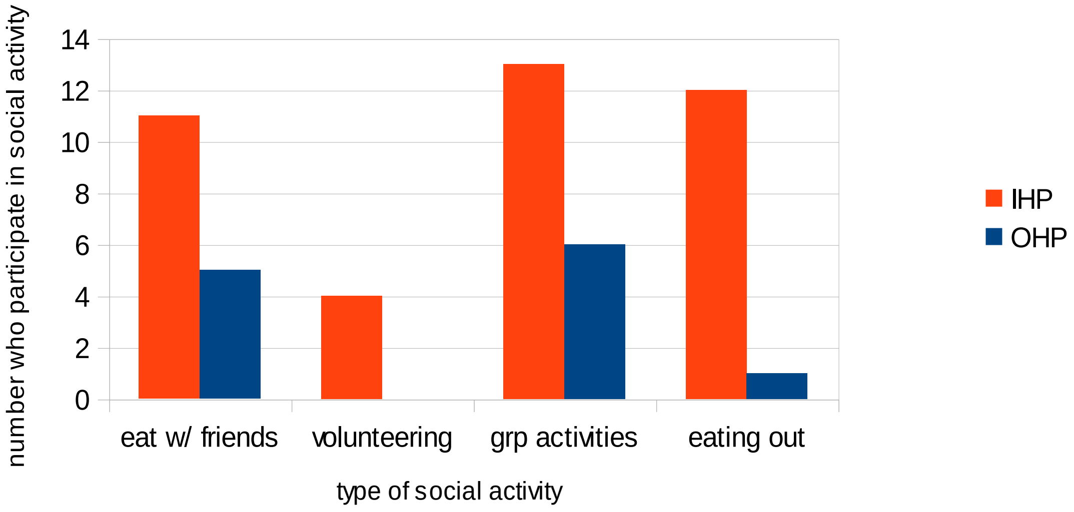


included scrap-booking, and talking with those who were part of the memories. Subsequent comparison by IHP and OHP of these reminiscing activities were: Looking at pictures (13:4), watching old home movies (9:1), reading old diaries (6:1), reminiscence therapy (2:4), and others (2:0). Although the difference between IHP and OHP appears large for looking at pictures, this is likely a result of a similarly disproportionate number of respondents. Looking at pictures was the most popular form of reminiscing among persons with AD with IHP and it tied for number one most frequent with formal reminiscing therapy for persons with AD in OHPs. (Figure 2.1)

Other types and levels of social activity, apart from reminiscing activities of the person with AD, were investigated in an effort to answer the first primary research question regarding what types of therapies and interactions are most effective in delaying the progression of AD symptoms. The type of social activity response choices included in the survey listed from most to least frequently participated were as follows: attending group activities (19), eating with friends (16), eating out (13), and volunteering (4). Subsequent comparison by IHP and OHP of these same social activities broke down as follows: attending group activities (13:6), eating with friends (11:5), eating out (12:1), and volunteering (4:0). (Figure 4)

Also of interest in the present study, embedded in the first primary research question, is whether or not the amount of communicative-interactions is beneficial in delaying the progression of AD symptoms. To answer this question, the questionnaire items elicited information on how much face-to-face interaction the person with AD has with meaningful people in their lives. In the IHP, 100% of the respondents reported their loved one with AD has meaningful interaction on a daily basis. This finding is hardly surprising since these particular persons with AD live with people meaningful to them. In the OHPs, 5 out of 7 responded their loved one has face-to-face interaction with someone meaningful every day. Of these, 2 out of the 7 responded that they interact with someone meaningful only a few times a week. These same two respondents also reported that their loved ones were diagnosed 7 years prior, suggestive of a more advanced stage of AD. In a similar vein, data was also collected on how often the respondent or other family members see the person with Alzheimer's Disease. The responses for IHP were everyday (11), multiple times a week (1), and once a week (1). Looking more

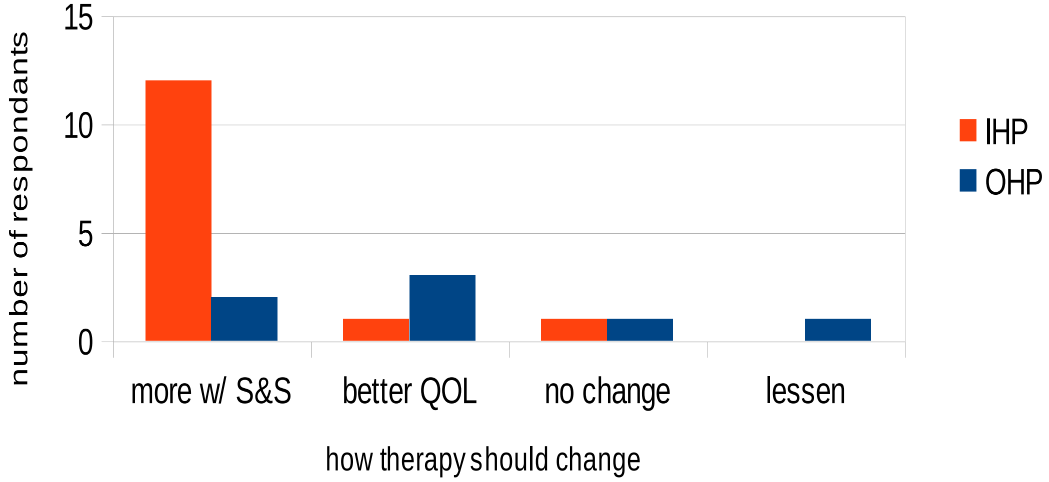
Comparison of Placement and Social Activities (Figure 4)



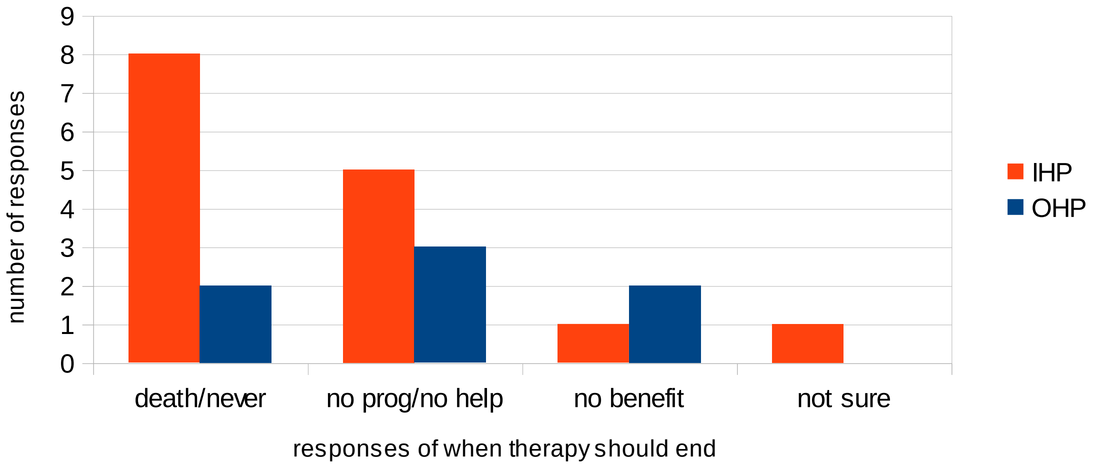
specifically at particular living arrangements in the IHP group, one person with AD who lives in their own home with unrelated caregivers reportedly sees family with the frequency of multiple times a year. In the OHP the frequency of family visitations were as follows: daily (1), once a week (1), multiple times a week (3), once a month (1), and multiple times a year (1). These results indicate those in OHP generally interact less with family members than those with IHP as a result of less frequent visits.

Another main line of inquiry in the present study sought to understand how the family's view regarding how the need for therapy changes as the disease progresses. A large majority, 19 out of the 22 (86%) responded that they thought therapy should change as the disease progresses. Data obtained in pursuing this strand of the inquiry consisted of responses to open-ended questions. Two themes emerged from the data regarding how the need for therapy should change as the disease progresses. One group of respondents indicated a preference for change in therapy with an increase in signs and symptoms (SS) and yet another theme that emerged was a change in therapy service that focused more on quality of life (QOL) issues. Of those that responded to these items, 14 responded that therapy should change with increased SS, however 4 respondents favored changes oriented towards improving the persons' with AD QOL. One respondent provided a more nuanced response that by its wording could have, arguably, been assigned to either category. Another two respondents stated they believe therapy shouldn't change or should stay constant as the disease progresses. One remaining respondent expressed the belief that therapy should decrease as SS increased. Figure 5 shows how the responses of how therapy should change varied between IHP and OHP.

Comparison of How Respondants Think Therapy Should Change and Their Loved One's Home Placement (Figure 5)



Data was also collected regarding respondents opinions on when therapy should be discontinued. Ten respondents indicated therapy should continue until death (45%), eight said it should continue until it is no longer helpful, or no progress is being made (36%), and three said it should end when there is no longer a benefit to the patient (17%).The respondents that indicated therapy should continue until death or until it is no longer helpful were more likely to indicate that therapy should increase with an increase in SS. All three respondents who indicated that therapy should continue until there is “no longer a benefit” to the person with AD also indicated previously that therapy should change in response to maintaining QOL. One respondent indicated that they were unsure when therapy should end, however their response to how therapy should change as disease progresses indicated they may have thought it should end at death or never. This respondent stated that therapy should “change as symptoms increase” and that it is “important to continue therapy as long as possible.” Figure 6 shows a comparison of IHP and OHP with respect to when therapy activities should be discontinued.


Comparison of When Therapy Should End and Home Placement (Figure 6)

Discussion

The present study aimed to determine, from the family's perspective, whether therapy or therapeutic activities and interactions are of value in the management of persons with AD. In doing so, an attempt was made to determine what activities were engaged in as the person with AD entered progressively more advanced stages of the disease. Furthermore, an attempt was made to ascertain family members' beliefs regarding the purpose of such activities as the disease progressed and their perceived effectiveness in delaying the progression of the disease.

Data obtained was used to address the primary research questions. Question one asked if there are certain types of therapies believed to be more efficient at delaying the progression of the disease. It was gathered that 100% of respondents believed in or supported therapy for their loved one at some point during the disease. The types of therapies mentioned were group therapy or support groups, medications, and therapeutic activities such as cognitively engaging tasks, non-cognitively engaging tasks, reminiscing activities, and social activities. Both group therapy or support groups and medications were commonly reported as types of therapies that were done with persons with Alzheimer's Disease. Both types of therapy were reported often in the IHPs. This suggests that these therapies were more common in the earlier stages of the disease.

Therapeutic activities shared a similar pattern. A greater variety and different types of therapeutic activities were done in IHPs as compared to OHPs. More cognitively challenging tasks, such as doing crossword puzzles, cooking, reading, and writing were reported more frequently for IHPs. These results support previous research documenting the decline in cognitive abilities at each stage of the disease (Cacace, 2007). As AD progresses, semantic and pragmatic abilities decrease, leading to decreased levels of participation in reading, writing, and crossword puzzle activities. There was also a complete drop in the playing of card games between IHPs and OHPs. Since most card games require cognitive skill and strategy, they will become increasingly difficult to participate in independently and even so with assistance. Board games, however, were one type of cognitive tasks that did not show a significant drop from in home to out of home placements. It is hypothesized that board games vary in level of cognitive difficulty. Hence they lend themselves more readily to participation with persons with a wider array of cognitive abilities. Additionally, assisted play from other players or assistants may also facilitate greater levels of social engagement and participation with board games as compared to card games. Board games also require participation in a group setting which is proven in research to be good at facilitating speech (Desai et al., 2009). Furthermore, board games can be easily played in a variety of settings. Overall, because many of these therapeutic activities are done in the IHPs, it is probable that such tasks are encouraged, initiated and facilitated by family members.

It has been suggested in previous research that participation in reminiscing activities are important for people with Alzheimer's to help retain past memories and, perhaps more importantly, stay current on past memories that have implications for current or future activities (Desai et al., 2009). The findings of the current study are supportive of these general conclusions. Looking at old pictures was the most popular reminiscing activity in both IHP and OHP even though the proportions reportedly engaging in looking at old pictures decreased in OHPs. Watching home movies was popular for IHPs. Presumably more readily available family or their spouse will be more likely to have them watch it. Reminiscence therapy was the only activity which demonstrated an increased level of participation from IHP to OHP. OHPs may have more specific programs for those with Alzheimer's to participate in when it comes to reminiscence therapy. This can include either group or individual therapy.

Staying active socially has also proved important to family members in this study. The majority of the respondents in both settings said that their loved one participates in some sort of group activity that encourages conversation and interaction. They also responded that eating with friends was a popular activity that remained important to their loved one even as the disease progressed to the later stages.

The first question also inquired about amount and nature of the AD patient's interactions with meaningful persons and family. They sought to see how often they had interaction in these various settings in comparison to their stage of the disease. It was determined that those in an IHP (less severe) had face to face interaction with somebody meaningful every day. This makes sense. However, 5 out of 7 in an OHP reported their loved one had a face to face interaction with a meaningful person every day. The lack of daily meaningful interactions of the two remaining respondents may be indicative of more advanced dementia characterized by a failure to initiate social interactions or even respond to social interactions which greatly hampers even structured efforts to promote social engagement.

‘Interactions with meaningful persons’ could refer to anyone that is close to the person with AD; however frequency of interactions with family members was of interest in the present study. Previous research suggested that family relationships are the lifeline to the person with Alzheimer's Disease and are often a part of the memories of the person, (Woods, 2001). Once again, in the IHP, the frequency at which the person with AD sees their family members is daily because they live with them. On the other hand, those persons with AD who live in an OHP see their family in person significantly less. With only one AD patient seeing their family in person daily, it may suggest that they are worse and do not know whether their family is visiting or not, therefore their family may not think it is as important to see and speak with them on a daily basis as in the earlier stages of the disease. As mentioned previously, AD is a progressive disease with no cure at present; management of AD involves attempts to delay the progression of symptoms for as long as possible.

The second question of this study sought to inquire about the family's perspective on how therapy should change depending on their loved one's placement. This raised the question of the purpose of therapy. A majority of respondents indicated that therapy should be based on the severity of the signs and symptoms, while others said it should be used to better the quality of life for the person with AD. An interesting finding in connection with this data was that the majority of the families reporting IHPs indicated that therapy should be based off the severity of the signs and symptoms their loved one was exhibiting. Most of these respondents had a loved one who was only 1-2 years post diagnosis. Their responses were typified by answers such as “more aggressive therapy” and “more often as symptoms become more severe”. However the families reporting OHP were more likely to respond that therapy should coincide with maintaining the quality of life for the person with AD. These respondents had a loved one with AD 6-7 years post diagnosis. They responded with answers such as, “should change to ensure quality of life at each stage of the disease” and “should have the end goal of keeping the patient busy and happy”. Two of the responses by family members reporting OHP indicated therapy shouldn't change or it should lessen. This leads one to speculate based off of other patterns emerging from the data that their loved one is most likely in the later stages of the disease and that extended periods of various therapies have failed to halt the progression of the disease. In the same sense, most respondents in the IHP responded that they believe therapy should end at death or never. These respondents’ family members were much more likely to be in early stages of the disease and hence more willing to advocate for an array of therapeutic efforts in hopes of delaying the onset of symptoms. However, respondents who had loved ones in the more moderate to severe stages reported that therapy should end when it is no longer helpful or the patient receives no more benefit. They express the belief that it is necessary, but there comes a point where it is apparent that the disease process is progressing in spite of all such efforts.

Limitations of the Study

While this study provided some insight into the research questions, it is not without limitations. The limited sample size is one such deficiency. Only 22 respondents participated in the present study seriously limiting the ability to generalize the findings to larger populations. The samples from each setting were also not equal. There were an insufficient number of respondents from the nursing home setting. Under a more structured sampling procedure more respondents from different settings would be proportionately represented in the study. Findings of the present study may be misrepresentative of a wider population due to the over representation of family members reporting an IHP. Another limitation was there were no means of establishing the nature of the relationship of the respondent to the loved one. This may have allowed the researcher to investigate whether some reporting biases of differences in actual involvement existed between different types of family members. For example, the closer the person is to their loved one (i.e., a son to a mother) may have affected their opinion on the value and duration of therapy. Yet another limitation of the study was a failure to take into account the gender of the person with Alzheimer's. Gender differences in types of activities may have obviously biased the type and amount of activities reported.

Future Directions

Despite its many limitations, the present study raised several interesting questions for further research. Future studies investigating factors positively impacting the maintenance of past memories and their role in helping the person with AD use such memories in order to understand current or possible future events to manage behavioral difficulties in AD would be a productive vein of research for refining and expanding a core of different reminiscence. Such a line of research might generate insight into issues related to both delaying the onset of symptoms in addition to improving the QOL of persons with AD and their family. The findings of the present study suggest that there are a variety of activities that seem to be important to not only the family, but the AD patient as well.

References

Alzheimer's Disease Education and Referral Center. (2010, December 8). Alzheimer's Information. Retrieved from http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/GeneralInfo/

Berrewaerts, J., Feyereisen, P., Hupet, M. (2007). Pragmatic skills in the early stages of Alzheimer's disease: an analysis by means of a referential communication task. *International Journal of Language and Communication Disorders.* 42(1), 1-17.

Briones, T.L. (2006). Environment, physical activity, and neurogenesis: Implications for prevention and treatment of Alzheimer's disease. *Current Alzheimer's Research*, *3*(1), 49- 54.

Cacace, A. T. (2007). Aging Alzheimer's disease, and hearing impairment: highlighting relevant issues and calling for additional research. *American Journal of Audiology.* 16.

Desai, A., Manepalli, J., Sharma, P. (2009). Psychosocial- environmental treatments for Alzheimer's disease. *Primary Psychiatry*, 16(6), 39-47.

Dye, C.D., Hoffmann, I., Irinyi, T., Kalman, J., Nemeth, D., Pakaski, M. (2010). Temporal Parameters of spontaneous speech in Alzheimer's disease. *International Journal of Speech-Language Pathology*. 12(1), 29-34.

Forbes- McKay, K. E., Venneri, A. (2005). Detecting subtle spontaneous language decline in early Alzheimer's disease with a picture description task. *Neurological Science.* 26, 243-254.

Herrmann, N., Gauthier, S. (2008). Diagnosis and treatment of dementia: 6. Management of severe Alzheimer disease. *Canadian Medical Association Journal*, *179*(12), 1279-1287.

Phillips, N., A., Taler, V. (2008). Language performance in Alzheimer's disease and mild cognitive impairment: A comparative review. *Journal of Clinical and Experimental Neuropsychology*. 30(5), 501-556.

Woods, R.T. (2001). Discovering the person with Alzheimer's disease: Cognitive, emotional, and behavioural aspects. *Aging and Mental Health, 5*(1), 7-16.

Appendix A

Family Members Survey

1.) Do you have a family member with Alzheimer's disease?
[ ] Yes
[ ] No

2.) How long ago were they diagnosed? (Specific in years)

3.) Where do they live?
[ ] own home
[ ] with family
[ ] assisted living facility
[ ] nursing home
[ ] other (please specify)
____.

4.) Do you think treatment/therapy is important for Alzheimer's patients?

5.) Which of the following are important things for your family member to participate in?

Cognitive Tasks
[ ] memory games
[ ] crossword puzzles
[ ] reading
[ ] writing
[ ] tasks requiring maintenance of attention (knitting, sewing, etc)
[ ] other (please specify)
____

Daily Activities
[ ] going for walks/ exercise
[ ] eating with others
[ ] watching TV
[ ] attending group activities (classes, meetings, church activities, etc)
[ ] other (please specify)
____

Reminiscing activities
    [ ] participating in group reminiscence therapy
    [ ] watching old home movies
    [ ] looking at old pictures
    [ ] reading an old diary
    [ ] other (please specify)

____

6.) If your family member receives treatment for things related to Alzheimer's, what kind is it? (Please list all therapy plans or medications related to Alzheimer’s)

7.) How often does your family member have face to face interaction with other people?
    [ ] multiple times a day
    [ ] a few times a day
    [ ] a few times a week
    [ ] once a week
    [ ] once a month
    [ ] hardly ever

8.) How often do you or other family members talk to the member with Alzheimer's disease on the phone?
    [ ] everyday
    [ ] multiple times a week
    [ ] once a week
    [ ] multiple times a month
    [ ] once a month
    [ ] hardly ever

9.) How often do you or other family members see the member with Alzheimer's in person?
    [ ] everyday
    [ ] multiple times a week
    [ ] once a week
    [ ] multiple times a month
    [ ] once a month
    [ ] multiple times a year
    [ ] once a year
    [ ] hardly ever

10.) How do you think therapy/ treatment should change as the disease progresses?

11.) When do you believe therapy should end?