Dementia: The Benefits of Talking

Leisure Connections is a social group for early dementia patients. Their (2011) goal is “to encourage, motivate, and educate people with mild dementia/Alzheimer’s to discover a better quality of life by increasing social interaction, sharing laughs, enjoying meals together, and developing new friendships” (p.113). They understand that people with dementia often feel lonely and forgotten. Dementia patients also have a hard time building and keeping healthy relationships. They feel that others do not want to interact with them because of their memory loss. Those kinds of feelings are exactly what Leisure Connections is trying to eliminate. They decided to conduct an experiment testing their belief that a social group could improve the quality of life of early dementia patients.

The experiment focused on three questions; what did the participants feel were the most important parts of the program, how did they feel about their involvement in the group, and how did they change throughout the program (Phinney, 2011, p. 114)? The experiment would consist of an interview portion and an observation. The researchers observed the participants for 40 hours and took notes on their interaction, group dynamics, and individual progression. They observed the group in different settings such as during casual conversation, meals, and recreational activities. After the experiment was conducted the researchers discovered seven themes within the group. The first theme they found was that everyone gets along really, really well. Phinney (2011) stated that Leisure Connections was “a tight cohesive group of people who genuinely enjoyed each other’s company…and support each other” (p.116). They also found that the group has more fun than anything, because they get to do activities they would normally not participate in. The third theme they discovered was stated by one of the male participants. He stated “we’re all old-timers and we know what that means” (Phinney, 2011, p. 118). He was referring to the fact that they all share a common bond, dementia. Although they don’t verbally discuss it, they can each relate to and understand what the group is going through. Another theme between the group is that they all felt they could be themselves. At first they were afraid there would be pressure to improve, but soon realized that “people are accepted for who they are” (Phinney, 2011, p. 120). The researchers also discovered that the participants felt wanted at Leisure Connections. The staff helped the patients feel important by letting them help with leading discussion, cleaning, or setting up activities. The sixth theme they found was that the group helped the patients come alive and get back to their old selves. The last theme they discovered was that the social group acted as a stepping stone for the participants. Many of them had feared joining a support group or assisted living facility, but after participating in Leisure Connections their eyes were open to the benefits of these organizations.

The number of dementia patients is rising and recreational therapists need to have the knowledge on how to work with them. Leisure Connections helped the participants build confidence in themselves and become more comfortable with their disease. The group also helped the participants grow socially and make better connections between other patients, staff, and family. Recreational therapists can use this knowledge when working with dementia patients to help them improve their quality of life.

There have been many experiments conducted on the importance of leisure for a patient with dementia. Most of these studies have confirmed that leisure activities can improve their quality of life. Recreational therapists know that patients will benefit the most from leisure if they participate in an activity they enjoy. However, there has been little research on what dementia patients consider to be important and meaningful activity. Phinney decided to conduct an experiment to address what dementia patients would like to achieve from their therapy.

The study focused on five questions about the patients’ leisure activities and how their diagnosis has affected their participation in them. The questions asked what leisure activities they were involved in, what this involvement meant to them, what their daily activities were, how the diagnosis has affected those activities, and how they will be affected in the future? The experiment was conducted on eight individuals with mild to moderate dementia. Interviews and observations were for 2-6 months. Four types of activities were found that seemed important to the patients; leisure and recreation activities, household chores, social involvement, and work related. Although the families of the patients admitted that their leisure activity had decreased, the patients will showed a great interest in their past hobbies such as crafts, playing piano, crossword puzzles, walking, and stamp collecting. Since their diagnosis household chores had become much more meaningful. Still being able to participate in their chores helped them feel like the illness was not controlling their life. Social involvement was still very important to the patients but they had a hard time interacting with people outside of their family and support group. They were uncomfortable and feared embarrassing themselves in front of friends. Work related activities also had importance to some of the patients. One man still worked as a choir director for his church. Another patient used to be a teacher and still found himself wanting to teach others with his wisdom. The experiment also found three themes to why the patients participated in these activities; enjoyment and pleasure, connection and belonging, and autonomy and identity. They pursued leisure they enjoyed because it helped them feel alive and forget about the dementia. Their leisure activities were also important to them because it helped them still feel like they were part of society. One participant voiced that when attending her daycare she was able to connect with others and help out during lunch. This helped her feel a sense of belonging and that her being there was important. Still participating in activities also helped the patients forget about their disease. They are often afraid of losing themselves in the dementia, but staying active helped them still feel in charge of their life.

After conducting the experiment, Phinney found that the patients’ interests resembled the interests of adults their age without dementia. Both groups understood the importance of staying active. Patients with dementia are also motivated to stay active because it helps them feel as if they are conquering their disease. Recreational therapists can use this information by helping the patients stay involved in past activities. By participating in activities of their pastime, the patients achieve a feeling of control and triumph over dementia.

Everyone has heard that first impressions are very important. How a person presents themselves can either make or break someone’s opinion of them. Cohen-Mansfield wondered if this same concept applied when introducing an activity to a nursing home resident with dementia. Does how the activity is presented affect the engagement and attitude of the resident? To test this theory they observed how modeling, the order of the presentation, time, and setting influenced the residents level of engagement.

The experiment involved 193 residents of a nursing home that had been diagnosed with dementia. Over a three week period, each participant was presented 22 different stimuli twice. Before conducting the experiment, several hypotheses were made. They predicted that the patients would benefit from a therapist modeling the activity for them first. When referring to the order of the presentation, they predicted that the residents would be more interested in the activity after the first presentation when compared to the second, because they would be less likely to remember the activity the second time. They also predicted that the morning hours would be the best time to present an activity, because the residents would be more awake. They also predicted that bright light, low noise, and few participants would help a resident be more engaged. After conducting the experiment, they made seven conclusions. They first found that the patients benefited from a therapist modeling the activity for them first. They also found that the residents were more interested in the activity after the first presentation when compared to the second. They tested the residents during the hours of 9:30-12:30 a.m. and 2:00-5:30. They had originally predicted that the residents would be more engaged during the morning, but the experiment concluded that they were more engaged in the afternoon. When testing to see how the patients responded when presented the stimulus on the same day versus on different days, they found the residents responded more when the stimulus was presented on the same day. After the experiment, they concluded that the residents had a more positive attitude when there was normal lighting. They found that dark lighting decreased engagement and bright lighting caused the patients to have a more negative attitude. When testing how the noise level affected the residents they discovered that moderate noise had the best response. No noise, little noise, and loud noise had a negative effect on the patients’ engagement. Lastly, they found that the residents felt more comfortable and interested when the activity involved 4-9 people.

How an activity is presented can be easily overlooked by a therapist. However, an activities presentation can have a big affect on the patients’ engagement and attitude towards it. Recreational therapist could use the information from this study when preparing to introduce a patient to a new activity. They should pay close attention to the environment surrounding the activity. Therapists should also make sure their initial presentation is clear and easily understood. This experiment could help therapists ensure the activity they are presenting makes a good first impression.
People engage in leisure activity because they receive some kind of enjoyment and satisfaction out of it. When making an activity plan for a client, therapeutic recreation specialists need to keep in mind what motivates or brings joy to the client. This also applies when finding reinforcers or preferred stimuli for older adults with dementia. In order to test the impact individualized stimuli has on a patient’s engagement, Feliciano decided to test how a predetermined reinforcer affected a patients’ level of agitation and depression.

Before performing the experiment, a number of tests had to be run to determine the participants’ agitation level, depression level, and what stimuli brought about the most enjoyment and engagement. In order to test the agitation level, the Cohen-Mansfield Agitation Inventory (CMAI) was used. Depression level was measured using the Cornell Scale for Depression in Dementia (CSDD). There were three tests used to determine the best stimuli to be presented during the experiment. The Motivation Assessment Scale measured what stimuli motivated the patients’ the most. The stimuli could either be classified as sensory, escape, attention, or tangible. The Pleasant Events Schedule and the Reinforcer Assessment for Individuals with Severe Disabilities was used to determine what activities brought the most joy to the patients. The experiment was broken into three phases. The first phase involved the experimenters choosing the eight stimuli that scored the highest to use in the experiment. During phase two the eight stimuli were placed in front of the patients. Each patient would choose any stimulus they pleased and the experimenter would record how long the stimulus kept them engaged. During phase three, depression and agitation levels were recorded using the CMAI and the CSDD. They concluded that using an appropriate stimulus decreased agitation level, but had little effect on depression level. Of the nine participants, six were no longer classified agitated according to the CMAI. Two of the four participants that had originally been classified as depressed had slightly decreased levels of depression, but the change was not significant.

Leisure activity not only delays the progression of dementia, but can also greatly improve the quality of life of a dementia patient. However, the preference of each individual patient needs to be taken into consideration. A recreational therapist needs to first understand what activities and stimuli motivate and engage the patient the most. They can then make an activity plan based not just on the patient’s needs, but also their wants. A patient will benefit the most when they are engaged in leisure activity that is individually designed to their preference.

When diagnosed with dementia, patients feel like they have lost all control. As they lose their memory, they may feel that they are losing their identity as well. Dementia patients’ relationships, cognition, and every day activities are affected. They fear losing their identity, personality, and feeling of self worth to the disease. Genoe decided to test the affect that leisure activity would have on helping maintain a person’s identity. He hypothesized that participating in leisure activity would help patients preserve their identity.

The experiment tested a small population of two men and two women diagnosed with dementia. The study took place over eight months and involved three ways of obtaining data. First they interviewed the four participants and asked them open-ended questions about their experience since being diagnosed. They also asked questions about their leisure activity and how it played a role in their identity maintenance. The second part involved a method called photovoice. Each participant was given a camera and asked to take pictures of things that had importance to them during their leisure time. The last part was an observation. The experimenters would participate in the patients’ leisure activities and take notes after the observation about their interaction, mood, and emotion. The study concluded that although dementia can discourage patients, it also can motivate them to do everything they can to not let the disease control their life. The study identified eight things the participants did to help them maintain their identity. By *sustaining valued aspects of self* they were able to convince themselves that they would not let the dementia change their identity. They would then *emphasize their abilities* by reminding themselves what activities they could still do despite the disease. Participants encouraged themselves to fight the dementia by *engaging in leisure, seizing new opportunities, and sustaining social personae*. During their leisure activities they were sure to *appreciate the simple things, have fun, and enjoy themselves*. The patients also found that *claiming a space* for them to do their leisure in helped to bring them comfort, safety, and a feeling of having a place all their own. Finally, the study found that leisure brought three benefits to the patients. It helped them create more memories, feel like they had a purpose, and gave them a sense of accomplishment.

People search to find their identity most of their life and hold tight to it once they find it. The diagnosis of dementia can cause someone to fear losing the identity they tried so hard to find. Participating in new and old activities can improve dementia patients’ confidence, sense of belonging, and quality of life. This study found that engaging in leisure activity can help patients maintain their identity.
Once diagnosed with dementia, older adults are more likely to withdraw and avoid social interaction. They find communicating with friends uncomfortable, because they are afraid they will make a mistake. Home-based care service for dementia patients normally only addresses the necessary things, like eating, cleaning, and hygiene. The social and mental health of the patient is often neglected. The Norwegian Department of Health believes that providing more day care centers would benefit people with dementia greatly. Brataas decided to do a study on exactly how a once a week day care center would affect the quality of life of people with mild dementia.

The program lasted for seven weeks and involved two groups of eight adults with mild to moderate dementia. Data was collected through interviews before, during, and after the program had finished. The staff asked the patients questions about what they expected from the group, their social experiences, how the events made them feel, and how it had affected their daily lives. The study found three themes that seemed constant from both groups: ambivalence shifts to interest, meaningful engagement engenders well being, and social fellowship promotes life contentment. “Ambivalence shifts to interest” had two phases. The first was insecurity, pertaining to the fear the patients had of social interaction. However, social motivation was the second phase. The patients may have felt uncomfortable in social settings, but they understood how important interaction was and wanted to maintain social health. “Meaningful engagement engenders well being” had three subgroups. The program provided from value-anchored self-expressions by incorporating old customs and past interests of the patients to help them maintain identity. The patients also gained a feeling of respect and security from the program, because the staff helped them feel important and accepted. Collaboration was also observed during the program. The staff and patients communicated and interacted well together and formed great relationships. The last theme was “social fellowship promotes life contentment”. It had three subgroups of sociocultural anchoring, cognitive stimulation, and vitality. Sociocultural anchoring took place when the patients discussed culture and customs. This helped the patients feel a sense of belonging, because they could comfortably discuss their past with one another. Cognitive stimulation took place during communication between the patients. They realized that by stimulating each other’s brains they could assist them in maintaining their memory. The patients also experienced vitality during the program. They were able to gain back their energy to stay active and social.

The study found that participation of dementia patients at a day care was beneficial to them in several ways. It helped them maintain their identity by incorporating cultural activities and discussions. The program made them feel a sense of acceptance and belonging because the staff and participants all worked hard to make each other feel respected. They also gained back their motivation and drive to stay socially active. The program opened the patients’ eyes and helped them feel alive again. Therapeutic Recreation Specialists could use this information when designing activities for a day care. Incorporating culture helped the patients rely on the brain to stimulate memory. Recreational therapists should plan activities that the patients would remember from their past, which would help with memory and maintaining identity.
Recreational Therapists work hard at planning activities that will interest patients and improve their disability. Therapists routinely question patients about their favorite activities and then modify them to the patients’ needs. However, personality may also play a part in patients’ interest level. Traits such as cooperation and agreeableness may affect how long the patient will engage in the activity. This study tested to see if a patient’s level of agreeableness influences the amount of time they stay interested in an activity made specifically for them.

The study involved 31 participants that had been diagnosed with dementia. First, the patients’ personality had to be tested using the NEO-FFI. It is a test that rates a person’s level of neuroticism, extraversion, openness, agreeableness, and conscientiousness. A person who had been in monthly contact with the person for the past 3 years, and had known them ten years prior to their diagnosis completed the test for the patient. The NEO-FFI results were used to test their level of agreeableness, place them in a study group, and create an activity for them. They used a person’s level of openness and extraversion to place them in one of four groups based on their preference of group or one on one and new or familiar activities. Once the tests were finished and the activities were planned the participants were introduced to the experiment. They were videotaped for three different sessions, involved in three different activities. During these sessions, the participants were measured on time on task and level of participation. The time ranged from 0-20 minutes. Level of participation was measured using a rating scale from 0-3. The score of 0 indicated that the person was sleeping during the activity, 1 reflected that the patient was awake but not engaged, 2 meant that the person was demonstrating passive engagement, and 3 showed the patient was fully engaged in the activity. After concluding the experiment they found that the results did not reflect their hypothesis. They had originally hypothesized that patients with higher agreeableness would show more engagement and stay engaged longer that individuals with low agreeableness. However, the results indicated that patients with low agreeableness participated in the activity just as long as patients that had tested with high agreeableness. This time was roughly 16 minutes for both groups.

Although the results did not reflect what was hypothesized, they still gained valuable information that can be used. When planning the experiment, an activity was made specifically for the patient. It had originally been assumed that someone’s personality would affect the patient’s level of participation in this activity. However, despite their score on the NEO-FFI, all of the patients’ engaged in the activity for the same amount of time. This information shows just how important every individual patient’s interests are. Therapeutic Recreation specialists must remember to always keep the patient’s specific wants in mind. When a patient is participating in an activity they enjoy they will be more likely to stay engaged, increasing their chances of improving their disability.
ART, activity reminiscence therapy is a program that uses the stimulus of old tools to help trigger someone’s memory. Therapeutic Recreation specialists often use leisure activities to improve a patient’s social, mental, and physical health. Patients with dementia need activities that stimulate their brain and memory recall. The use of ART and brain-activating activities could greatly benefit a dementia patient. This study used the ART method to test how brain-activating activities would improve the symptoms of dementia.

The study 3 evaluations and 2 ART interventions. Two evaluations were preformed 3 months apart, before the interventions. The interventions took place over 3 months and involved one session a week. There were 18 participants broken into 3 separate groups. The evaluation consisted of 2 parts, video and testing. In the first 10 minutes, the participants were given a preview of how the intervention would work. They were shown a video of different tools. They were all then given an opportunity to demonstrate how to use the tool. After the video activity, the participants and family members completed several tests such as the Mini-Mental State Examination, Kana Pick-out Test, and the Wechsler Memory Scale-Revised. After the first to initial evaluations were made, the participants started the intervention. The patients would participate in the tool activity for one hour each week. During the intervention, the experimenters were trying to answer two questions. The first involved how the participant changed after the intervention. The second question was asked to the staff about how their physical care and social interaction changed between them and the participants. The study found four themes surrounding the intervention. The staff and family members provided most of the feedback on how the participants had changed. First, they found the participants become more cheerful and positive. Next, they commented that they had a more positive anticipation of ART. The family mentioned that the participants would prepare for the ART session by picking out their clothes ahead of time and fix their hair. The family and staff also noticed an improved peer relationship. The recalled that one lady that had originally avoided all social contact, started to reach out to the group. They also stated that one woman had normally stuck to one friend but eventually branched out and made new relationships. They also recognized a more cooperative attitude toward the care staff.

The study found that the ART session did help improve the memory recall of the participants. They concluded that the program may have been so successful because they used old, familiar tools to help activate their memory and incorporated role-reversal. The staff was not familiar with the tools being used so the participants were able to feel important because they were teaching the staff something new. Therapeutic Recreation specialists can use this information by incorporating familiar tools into their therapy plan. Dementia patients have a better chance of recalling memories if they maintain interaction with familiar things. They could also involve role-reversal to help the patients feel important, useful, and confident.
Review of Articles

Most people understand that when an older adult is diagnosed with dementia, it means that they will have a hard time recalling old memories and creating new ones. However, this definition only scratches the surface of the affects dementia can have on someone. The underlying symptoms are often overlooked, such as social withdrawal, decreased self-esteem, impaired identity, and a negative outlook on life. In order for a recreational therapist to do their job successfully, they must fully understand the extrinsic and intrinsic affects a disability can have on an individual. After reading several scholarly articles on leisure and its effects on dementia, I was given new insight on how important leisure can be in improving and possibly delaying the onset of dementia. The information gained from these articles can benefit my personal life, the life of people with dementia, and my future career as a recreational therapist.

I was not able to find a study that supported the hypothesis that leisure would decrease the risk of developing dementia, but I was able to gain knowledge on how to deal with dementia in my life and my family life. I understand that it is a possibility that a family member may be diagnosed with dementia. If this is to happen I will know that they will be very scared about losing their identity, embarrassing themselves in front of friends, and falling out of touch with the world. I can help eliminate some of these feelings by keeping them active and involved in outside activity. I can help their friends understand how dementia will affect my family member, and how they can help them feel more comfortable. Most importantly, I can help my family member feel respected and accepted for who they are, so they remain confident in themselves and eager to stay active in life.

After reading the articles, I attained a lot of knowledge on how beneficial leisure can be in decreasing the symptoms of dementia. Leisure was proven to help patients maintain their
identity (Genoe, 2011), improve their outlook on life (Genoe, 2011), bring them a sense of belonging (Phinney, 2007), and improve their memory recall (Yamagami, 2007). When dementia patients participated in leisure activities from their past, they were able to stay connected to their personality (Genoe, 2011). Staying active also helped them forget about their disease and feel alive again (Genoe, 2011). They felt a sense of belonging, because when they did activities in the community they were able to stay connected to society (Phinney, 2007). Studies also have shown that when dementia patients participated in activities from their past they were able to recall past experiences (Yamagami, 2007).

I can also use the information I learned from the articles in my future career as a recreational therapist. I learned the importance of using activities the patient enjoys for their therapy. Studies have shown that tailoring an activity to a person’s interests will decrease their agitation (Feliciano, 2009). It has also been proven that if a person is engaged in an activity they enjoy then their disagreeable behavior may be counteracted (Hill, 2010). I also learned that how an activity is presented can affect a patient’s engagement (Cohen-Mansfield, 2010). In order for an activity to be successful it needs to be introduced clearly and placed in a comfortable setting.

Dementia is likely to affect everyone at some point, whether they or a loved one is diagnosed. Understanding every symptom that accompanies dementia can help people know how to better help themselves or the family member. Being a recreational therapist I will have to prescribe an activity plan for patients with dementia. After reading these articles I was able to gain information on dementia and the many benefits leisure can have on it. Besides memory recall, leisure can benefit a patient’s mental, emotional, and social well being.