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Exploring the Use of Mindfulness with Individuals Diagnosed with Alzheimer's Disease

by

Gina L. Hemmesch, BSW, LSW

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of
Master of Social Work

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The Clinical Research Project is a graduation requirement for the MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Alzheimer's disease is one of the leading causes of death in the United States. This is a progressive disease with no cure. Are there interventions available to give individuals with Alzheimer's disease hope? One such intervention is the use of Mindfulness practices. The purpose of this research is to explore how professionals working with individuals with Alzheimer's disease use mindfulness in their practice and what the benefits of using mindfulness may be. Using a qualitative design, three participants were interviewed who use mindfulness with individuals with Alzheimer's disease. The data was analyzed using inductive coding of the research. Four themes were identified. These included, benefits of the use of mindfulness with AD, lowering distress and stress in individuals with AD when using mindfulness practices, the stages of AD that would benefit from mindfulness, and the training and education needed on mindfulness when working with individuals with Alzheimer's disease. The use of mindfulness practices offers hope to individuals with Alzheimer's disease. The research on mindfulness practice is relatively new and more research is needed. As our country continues to get older and more individuals develop Alzheimer's disease more research on effective treatment options is needed.

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Alzheimer's disease (AD) has become one of the fastest growing causes of death over the last decade, as deaths from AD have increased by sixty-eight percent (Alzheimer's Association [AA], 2014a). According to the Alzheimer's Association the number of people that will be diagnosed with Alzheimer's disease will triple in size (2014a). What programs are available to assist someone who has been diagnosed with this terminal illness? As there is no cure for this disease, looking at alternative methods to help someone with this disease may be helpful for professionals who work and care for individuals with AD.

Recent research suggests that one alternative method would be mindfulness. Some studies suggest that the practice of mindfulness causes the reduction of someone's stress level and others claim that mindfulness can increase someone's cognitive abilities (Baer, 2006; Chiesa, Calati, & Serretti, 2011; Larouche, Hudon, & Goulet, 2014; Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010; Paller et al, 2014; Rejeski, 2008) Mindfulness has been shown to reduce anxiety and depression in people that practice mindfulness, but can this be helpful to people with AD?

Research states that people with AD can be helped with the practice of mindfulness, but is this practice being used? Mindfulness practice can reduce anxiety, depression, stress and even increase cognitive abilities in someone with AD (Chiesa, Calati, & Serretti, 2011; Larouche, Hudon, & Goulet, 2014; Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010; Paller et al, 2014; Rejeski, 2008). How do practitioners working with people with AD use mindfulness in their practice? At what stages of the disease is mindfulness practice used? Are there specific mindfulness practices that offer more of a benefit to the person with AD?

This research paper will look at answering some of these questions by using qualitative research design. This researcher will ask professionals who are working directly with

individuals with AD about their use of mindfulness in their work. The researcher will also explore the topic of using mindfulness when individuals have a diagnosis of AD with mindfulness professionals to collect information on how mindfulness could potentially be used with this population. The researcher will also look at the question of what is known to the professionals about mindfulness and what may be lacking in the knowledge of professionals who work with individuals with a diagnosis of AD.

This research will help professionals working with individuals with AD, by giving them some ideas to move forward in the practice of mindfulness. This research is intended to look at an area that has been shown to be helpful to individuals with Alzheimer's disease. As there is no current cure for AD the ending is the same for everyone one with this disease, but mindfulness may lessen the burden of the journey. The idea that mindfulness practice can increase the cognitive ability of someone with AD is exciting to explore further. This research can give some hope to individuals diagnosed with AD. The purpose of this research paper is to examine how mindfulness practice is used with individuals with AD and what benefits practitioners are seeing with this practice.

Literature Review

The research literature on the use of mindfulness practices with individuals with AD is limited. This is a new area of research for AD and mindfulness. Mindfulness is a practice that is used with many other diagnoses and has been shown to be helpful. Mindfulness has also been studied and shown to benefit older adults. The practice of mindfulness may have some benefits to those with memory loss and AD.

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia which causes memory loss and interferes with how someone is able to participate in daily life (Alzheimer's Association [AA], 2014a). Alzheimer's disease affects over five million Americans and every 67 seconds someone in the United States develops this disease (AA, 2014a). Alzheimer's disease is progressive and will continue to affect someone's ability to care for themselves to the point that they will no longer be able to care for themselves and eventually leads to death. AD can cause a huge burden for families who are caring for someone with this disease. In the United States it is estimated that the cost of caring for people with AD is \$214 billion dollars (AA, 2014a). The cost and emotional burden for someone with AD can be devastating.

AD was named after Alois Alzheimer in 1907 as he was the first person to fully examine an individual with this disease and look for the causes of the disease. Dr. Alzheimer studied the brain tissue of a patient who had been experiencing memory loss and disorientation. What he found were plaques and tangles in the tissue that causes the brain damage in patients with AD. (as cited in Castellani, Rolston, & Smith, 2010). Since that time more information has been learned about the disease and how it works, but still no cause or cure has been identified. Research is continuing to look for both a cause of AD and a cure for AD. While a cure is being

found, social workers and other professionals need to look methods for treating some of the symptoms that AD causes.

Most people are aware that the main symptom of AD is memory loss, but that is not the only symptom. As AD affects the brain, it eventually causes damage in all areas that the brain is responsible for, including the ability to walk and talk. As AD progresses, more symptoms present themselves and can include memory loss, disorientation, changes in mood, behavior, and personality, and even paranoia, delusions, hallucinations (AA, 2014c). People with AD are also commonly diagnosed with anxiety, depression, and insomnia (AA, 2014c)

AD is sometimes referred to in the context of Alzheimer's disease and other related dementias. AD is one type of dementia, but there are many others. These other dementias include but are not limited to vascular dementia, Parkinson's dementia, Lewy Body Dementia, Frontal Temporal Dementia, and mixed dementias (AA, 2014d). Dementia symptoms of mental decline are present in all of the previous listed dementias, but memory loss in AD is usually a first sign of the disease. The hallmark of AD is memory loss, where many of the other dementias do not demonstrate memory loss symptoms until further along in the disease process. The focus of this research will be on AD and memory loss. Mild cognitive impairment (MCI) is a term that may also be used when talking about individuals with memory loss. Individuals with MCI have a higher risk of developing AD (AA, 2014e). Individuals with MCI show a slight, but noticeable change in their memory or cognitive abilities (AA, 2014e).

Medical Treatments for Alzheimer's disease

Most of the treatments used for AD are to help control the symptoms. The medications that will be named in the following paragraph are primarily used to control the symptoms of memory loss and cognitive decline. For other symptoms of AD, both pharmacological and non-

pharmacological interventions are used. To control some of the mood and behavior issues that someone with AD experiences, anti-depressants, anti-anxiety and anti-psychotic medications have been prescribed (AA, 2014c).

Medications are being prescribed to treat AD. These medications are either a cholinesterase inhibitor like Aricept, Exelon, or Razadyne or glutamate receptor antagonist, Memantine (AA, 2014b). These medications are not a cure nor do they shorten the disease, they only control the symptoms for a period of time. The use of these medications offer a stabilization of the disease process (Feldman, 2002). As AD progresses into later stages social workers, nurses, or doctors have conversations with families about the usefulness of these drugs. Even though these medications only offer benefits for a short period of time, many families are reluctant to stop these medications as they perceive a benefit to continuing them.

Mood and behavior issues are common with individuals with AD. Because of the changes in the brain that happen with AD, the individual may have difficulty controlling emotions. This can lead to poor impulse control and aggression. As the disease progresses difficulty with communication becomes an issue also. Because of the inability of someone with AD to understand and communicate, many times additional medication is prescribed to control these mood and behavior symptoms instead of trying non-pharmacological interventions.

Non-medical Treatments for Alzheimer's Disease

Non-pharmacological interventions can take many different forms. As with most interventions, these have to be personalized to the individual with AD. An intervention may work for one person and may not work for another. One of the first interventions that is needed when diagnosed with AD is education about the disease for the individual and family. Many times this education is done by a social worker. Knowing more about the disease and how it

progresses benefits the individual with AD and the people who are assisting with the care needs of the individual. Knowing what to expect and working with a social worker or other professional to develop a plan reduces the stress of making decisions as they arise. Financial decisions, health care decisions and housing decisions are all areas that can be discussed and planned for.

Other non-pharmacological interventions that can be effective include areas of interventions that examine the environment and personal self for triggers or stressors. Being alert to any medication changes, infections, pain, or emotional distress are necessary for the caregivers of someone with AD (AD 2014c). Adding structure to the day with activities and socializing can also play a role in assisting someone to cope with the disease. Giving structure to one's day allows someone with AD to also improve their sleep pattern (Vance and Cowen, 2003). Music is also an intervention that works well with calming the mood and behavior issues that one may be experiencing with AD (Nair, Browne, Marley, & Heim, 2013). Music can also have an effect on increasing language skills (Brotons, 2000). All of these interventions can be tried and some may have a varying degree of success at different times in the life of an AD patient. It is also important to note that these interventions need to be individualized to maximize the benefits for someone with AD.

The saying of "use it or lose it" has some truth to it when it comes to Alzheimer's disease. As with most disease the best treatment is to reduce the risk of developing the disease. The best risk reduction is leading a healthy lifestyle. That healthy lifestyle would include eating right, and exercising, as some studies show a link between obesity and AD (Seshadri, 2010). With AD and other dementias, that would also include exercising the brain. Brain exercises have been shown to delay the onset of AD (Willis et al, 2006). These brain exercises include doing

puzzles like crosswords and Sudoku or even simple changes in life such as changing your routine by using a different hand to brush hair or taking a different way to work. Another component of living a healthy lifestyle is socialization. Having an active social life is important for brain health.

The idea that you can reduce your risk of developing Alzheimer's disease is one that needs to be explored further. Some researchers believe that high levels of stress and depression can lead to someone developing MCI or AD sooner than someone who is not depressed or stressed (Larouche et al., 2014; Wells et al., 2013). Preventing someone from developing AD may not be totally possible as currently the cause of the disease is still being researched. The idea that the disease may not be prevented, but delayed a few years is still an exciting one to explore further.

In the past, much of the focus about Alzheimer's disease has been on the caregiver and supporting the caregiver through the process of the disease. With advancements in the diagnostic testing of AD, individuals with the disease are getting diagnosed earlier in the disease process. Individuals with AD are much more able now than ever before to participate in their treatment plan. Researchers at the Mayo Clinic and around the world are exploring ways to diagnose someone with AD even prior to the presentation of symptoms. This research can be exciting and terrifying. As there is no cure for the disease and no treatment that has been proven to even slow down the disease process, this may look like a bleak future to many with AD. More research needs to be done with individuals with AD and what treatments may show positive benefits. One area that recent studies are showing having a positive impact is the use of mindfulness practice with AD.

Mindfulness Practice

Mindfulness practice has its roots in the eastern religion of Buddhism, and has been adapted to western culture. According to Kabat-Zinn, "Mindfulness means paying attention in a particular way: on purpose, in the present moment, and non-judgmentally" (1994, p. 4). Focusing on the present or being mindful of the present without having expectations of what the future may hold, would appear to be helpful to someone who has AD. As with AD, the present may be the only place that one may be able to focus on at the moment as memories of the past may be gone and the idea of a future may hold too many unknowns.

There are different forms of mindfulness practice that are currently practiced in the western world. Mindfulness interventions can be as simple as meditation or bringing mindfulness to daily life such as being mindful when eating or walking. Some forms of mindfulness use exercise to make a mind-body connection like yoga or tai-chi.

More formal mindfulness practices are used in more of a clinical setting. These include mindfulness based stress reduction (MBSR), mindfulness-based cognitive therapy (MBCT), dialectical behavior therapy (DBT), and acceptance and commitment therapy (ACT) (Baer, 2006, p. 4). MBSR and MBCT are more structured mindfulness approaches used in a clinical setting. Other approaches pulled from MBSR and MBCT are used on an individual basis, including the raisin exercise, body scan, sitting meditation, yoga, walking meditation, and being mindfully aware in daily life (Baer, 2006, pgs. 6-10).

MBSR is an intensive training program on mindfulness that is done in a group format, typically for individuals with stress, anxiety, depression, and/or chronic pain (Kwasniewski, 2008). Typically, MBSR is an 8 week class meets once a week for 2 to 3 hours and then given homework to practice mindfulness at home (Baer, 2006, p 6). One of the exercises done in

MSBR is the raisin exercise, which is an exercise that asks participants to focus on a raisin in all of its contexts including the texture, smell, and taste and only focus on the raisin (Baer, 2006, p. 7). The Body Scan is another technique that is used in MSBR. The Body Scan consists of lying or sitting comfortably and scanning through all of one's body from head to toe and noticing all the parts and how they are feeling, but not necessarily to change how the body is feeling, but to learn how to pay attention (Baer, 2006, p. 7). Sitting and walking meditation and Hatha Yoga are also done within this 8 week program. The focus for these last three is continuing to focus on awareness of one's body and breathe while doing the exercise (Baer, 2006, p. 9).

To use MBSR in one's own practice, a person would need to be trained. According to Baer that training would be need to be extensive. "Minimum qualifications include a master's degree in a mental health field; daily meditation practice; attendance at two silent, teacher-led meditation retreats of 5-10 days duration in the Theravadan or Zen traditions; 3 years' experience with Hatha yoga or other body-centered disciplines; 2 years' experience teaching stress reduction and yoga or other body-centered discipline in a group setting; and completion of 5- or 7- day residential professional training in MBSR" (2006, p. 13). For someone to be using MBSR, they have to have all of the training and continue to use the mindfulness skills on a daily basis in their own life. Do people who use mindfulness in a professional setting also practice it in their personal life, as is recommended? Many clinicians are taking some of the aspects of MBSR and applying it to fit to the particular setting that they are working with. For this research, examining the background and qualifications of clinicians using mindfulness practices with individuals with AD is something to explore.

MBCT is another eight week group format mindfulness training, but it is more focused on depression and relapse (Wisniewski, 2008). MBCT uses the interventions from MBSR in its

programs, but then also adds a few new exercises. These include more focus on bringing thoughts and feelings into a session and also dealing with automatic thoughts, then applying this to relapse prevention (Baer, 2006, p. 14). Baer states that there is no qualifications needed to lead an MBCT training, but recommends that one is using mindfulness in their own life (2006, p. 14).

For the sake of this research paper DBT and ACT will not be explored as no research has been found to connect these two formal mindfulness practices with AD. The focus will be on MBCT, MBSR, meditation, yoga, and daily mindfulness practices.

Benefits of Mindfulness

The practice of mindfulness can be applied to many different disorders. Mindfulness is known to have benefits when used to control and lessen pain (Rejeski, 2008). Mindfulness also has a role in reducing stress (Baer, 2006, p.6). Mindfulness practices are also known to be helpful with other mental health disorders such as depression, and anxiety. (Moss et al., 2012; Baer, 2006, p. 192) AD can cause higher instances of depression and anxiety than other individuals who do not have this disease (Knapskog, Barca, & Engedal, 2014). Mindfulness practice appears to be a good fit for older adults as many older adults experience pain and stress. Older adults also suffer from mood issues. Most of the individuals with AD are also over the age of 65 and considered to be elderly or an older adult. As one gets older the experiences of grief and loss may also increase. Grief and loss can also be an area that mindfulness can have a role in helping (Doswell and Martin, 2012). The use of mindfulness practice in older adults would appear to be a natural intervention to consider.

Mindfulness with Older Adults

The perception that older adults are reluctant or hesitant to try new and innovative therapies is simply no longer the case. As baby boomers are aging and becoming older adults, the idea that an older adult is someone who is not comfortable with new ideas is not true. More research needs to be done with older adults and the use of mindfulness practices, but the results of the recent studies appear to be positive (Rejescki, 2008; Doswell and Martin, 2012). Older adults who use mindfulness practice in their daily life along with physical activity appear to have the best results and continue to benefit from the practice of mindfulness when not actively practicing (Rejescki, 2008; Doswell and Martin, 2012.)

As with younger individuals, mindfulness may work well in recovery for older adults who are experiencing anxiety and depression. One research study using MBCT showed a reduction in depressive and anxiety symptoms in older adults (Fouk, Ingersoll-Dayton, Kavanagh, Robinson, & Kales, 2014) Another study that used only meditation also showed similar improvements with mood and anxiety (Moss et al.,2012). Another study shortened MBSR to 30 minute sessions over four days, and showed no change in someone's well-being (Hubbard, 2011). As there are not a lot of studies done with mindfulness and older adults it is difficult to say conclusively if the practice adds benefits for an older adult who is experiencing depression and anxiety; however, results are promising. The type of mindfulness approach may also have an impact on the results of the study and this would also need to be explored further

Mindfulness with Alzheimer's disease.

A recent study looked at individuals with Alzheimer's disease and individuals with mild cognitive impairment (MCI) and the effects of mindfulness training. This study considered many different areas of life that can be affected by Alzheimer's disease. It examined quality of

life, depression, sleep quality, anxiety, patient behavior, activities of daily living and cognitive areas. The areas that showed improvement for patients with Alzheimer's disease were in quality of life and depression. The other areas tested showed no significant differences (Paller et al., 2014).

Some researchers are hoping that the further use of mindfulness techniques with individuals with Alzheimer's disease and MCI could reduce the onset of the disease by 5 years. The thought with this is that depression and stress can lead to the early development of Alzheimer's disease, but that the use of mindfulness could delay the further cognitive loss of the disease. At this point this is just a theory and has not been proven (Larouch et al., 2014). Further research continues to be needed with this hypothesis of mindfulness causing the delay of cognitive loss.

A systematic review of neuropsychological findings examined this idea of a connection with mindfulness training and improved cognitive abilities. The results of this research showed that the use of mindfulness could have benefits on cognitive abilities, including memory, of individuals with Alzheimer's disease and MCI (Chiesa et al., 2011). This research is still in the very early stages, but shows some promise. Future research with using mindfulness practice with AD needs to continue. Currently this research shows promise in the ability to improve cognitive functioning.

The research literature that examines the use of mindfulness has not specifically looked at people with the diagnoses of AD. Most of the research focuses on people with memory loss or mild cognitive impairment (MCI), but does not specifically give a diagnosis (Wells et al., 2013; Moss et al., 2012; Hubbard, 2011). Only one study that included people with MCI also had people with a formal diagnosis of AD (Paller et al., 2014). More research needs to be conducted

that focus on individuals with a diagnosis of AD and not just memory loss. Other areas to examine would be to look at the individuals with MCI or those reporting memory problems and see if AD is later diagnosed for them.

The research that has been done has been on a very small scale. All of the research that has been conducted on the use of mindfulness practices have a range of participants from 7-20 participants in the study (Hubbard, 2011; Moss et al, 2012; Newberg et al., 2010; Paller et al., 2014; Wells et al., 2013). The reason for the small sample sizes can be easily explained by how mindfulness is typically practiced. As mindfulness practices such as MSRB, meditation, or yoga is done in a small group setting this would be hard to duplicate in a large setting or sample size. Therefore the research needs to be replicated many times to find out if it is beneficial on a larger scale.

It is also interesting to note that in the research literature examined, only one listed the mindfulness background and training of the researcher in the methods section (Foulk et al., 2014). According to Baer, for someone to use MBSR they need to be qualified to teach mindfulness and as stated earlier this training is extensive and for other areas of mindfulness training is not necessarily required (2006, p. 13). What is the training of the individuals that are doing the research and would this have a bearing on the results of the research? There is an assumption that the researchers are master level or above in their training, but what is the separate training in mindfulness?

The use of mindfulness practice in a clinician's practice would be an area to research further. As this area is relatively new, it would be beneficial to get the perspective of the clinician who is using mindfulness practice in their work with AD. What are the benefits that they are seeing, if any? Would this be an area that clinicians need more training on to be a

successful practitioner? The purpose of this research paper is to examine how clinicians or memory care professionals use mindfulness practice, whether it is MBSR, MBCT, yoga, meditation, or daily mindfulness, is used with individuals with AD and what benefits are practitioners seeing with this practice.

Conceptual Framework

Over the last 15 years, I have been a social worker in a nursing home setting. Most of the individuals that I have worked with have been diagnosed with Alzheimer's disease. Working with individuals with AD and their caregivers over the last 15 years has made me ask more questions about the disease of Alzheimer's than I can find answers for. Families and the individual with AD are looking to me as the social worker as the individual that will somehow make that miracle happen and the disease will be gone. Repeatedly telling someone about the disease without offering some hope has made some of my job over the last few years difficult. As a social worker, I am always looking for that hope.

Social workers are trained in the strengths based perspective that was developed by Dennis Saleebey of the University of Kansas. The elements of the strengths based perspective that Saleebey talks about are first always "believe in the client", second "affirm and show interest in the client", third "a focus on the dreams, hopes, and visions of people encourages them to begin thinking...about what might be and how it may come about", fourth "begin making an accounting of the assets, resources, reserves, and capacities within the client and in the environment" and fifth "there are forces of healing, self-righting, and wisdom" that someone has or is surrounded by in their environment (Saleebey, 2000).

Saleebey also talks about some key words that are used in conjunction with the strengths based perspective, these words are empowerment, resilience, and membership (Saleebey, 1996). These words play a key role in a social workers practice. A social workers job is to help an individual and their family to heal and find hope and resilience (Saleebey, 1996).

When working with individuals with AD finding some hope and resilience is at times difficult. Since AD disease is a terminal illness with no known cure, at the time that this paper is

being written, finding ways to offer individuals some hope and resilience in the face of this disease can be difficult. Looking for hope and resilience to give to individuals with AD is a goal that I have had when working with individuals with AD. Even if it may be a small hope it is better than a focus on the continued knowledge of a terminal condition.

Using mindfulness practice with individuals with AD would show that hope and resiliency that many may look for. When a clinician offers the intervention of mindfulness practice to someone with AD it shows that the clinician believes in the individual and shows interest in the individual. The use of mindfulness practice with individuals with AD would help to center that person to focus on the capacities that are available at the moment. Using mindfulness with individuals with AD would also be an opportunity for that individual to focus on healing capabilities that may be within them and their environment.

Having some positive research available to give to families searching for something new to focus on would offer that hope and resilience when dealing with Alzheimer's disease. Even though the research on the use of mindfulness with Alzheimer's disease is still in the earlier stages, it is showing some positive results. As discussed in the literature review some use of mindfulness practice in individuals with AD has shown to have some positive results. The reduction of stress, anxiety, depression and possibly even some changes with memory are all areas that can offer some hope to someone with AD.

Methods

The method of research that was used for this study was a qualitative study which including interviewing individuals who had knowledge about mindfulness and were willing to answer questions as to how mindfulness is used or could be used when an individual has a diagnosis of AD. The qualitative research that was conducted used availability and snowball sampling to find participants for the research. The subjects are professionals who work with AD and use mindfulness practice in the context of their employment and professionals who used mindfulness and have an interest in how it can be used with people diagnosed with Alzheimer's disease. Thirteen questions were asked of these participants. The information gathered was reviewed for themes and then analyzed using grounded theory.

Human Subjects

Participants for this study were identified and recruited using several methods. First participants were recruited from a list of professionals who belong to an organization called Memory Care Professionals (MCP). Members of this group are all professionals working with individuals with memory loss. These professionals include social workers, nurses, chaplains, administrators, marketing and activities professionals. Membership to this group is free; anyone with an interest can join. The group meets quarterly and also has a group on the social media site Linked-In. Any member of the group can post on the Linked-In site with updates or questions. This researcher posted a request for research participants on this site with the researcher's contact information. Interested participants emailed this researcher separately from the Linked-In site thereby maintaining confidentiality. Secondly, due to lack of respondents from this recruitment, subjects were also obtained from personal contacts that had knowledge in this area. Emails were sent out to personal and professional contacts that were known to this researcher

with a request to ask for potential participants and to forward on this researcher's contact information to these potential participants. A request for participants was also emailed to professional centers that offer mindfulness training.

This project met the approval of the University of St. Thomas Internal Review Board in regards to the protection of human subjects. The subject's identity has been kept confidential by the researcher. The identity of the individuals being interviewed have not been shared with anyone and the interviews were only transcribed by the researcher. The subjects signed a consent form that explains how the subjects' identity are kept confidential (see Appendix A for copy of consent form). This consent form has been kept in a locked file in the researcher's home and will be kept for three years and then shredded. Any other identifying information has been kept confidential.

Data Collection

Interviews were conducted in person with the subjects. The researcher interviewed three subjects who are professionals who work with individuals with AD. The questions that had been asked, were developed after examining the literature as it relates to the use of mindfulness practice with individuals with Alzheimer's disease. The length of the interviews ranged in length from 16 minutes to 38 minutes. The interviews were audiotaped and then they were transcribed by the researcher. The interviews were conducted at the interviewee's preference which included offices and coffee shops.

There will be a total of 13 questions asked of the subject. Clarifying questions were also asked of the participants when the researcher did not understand the response of the participants. At the end of the interview a final question asked if the respondent wanted to add any other

comments or statements about how mindfulness is used with an individual with Alzheimer's disease.

The questions are included below:

Questions for Interview

- 1) What is your educational background?
- 2) What is your training in Mindfulness?
- 3) Do you practice mindfulness in your own life? How long have you practiced? Examples?
- 4) How many years have you worked with individuals with Alzheimer's disease and in what setting?
- 5) How long have you used mindfulness in your professional life?
- 6) In what way is mindfulness used in your work setting? (Types used?)
- 7) How is it used with individuals with Alzheimer's disease?
- 8) From your experience what benefits do you see with mindfulness practice?
- 9) From your experience what negatives do you see with mindfulness practice?
- 10) Is the use of mindfulness different when someone has Alzheimer's disease?
- 11) Have you experienced any challenges with using mindfulness practices in your setting?
- 12) What stages of Alzheimer's disease do you see mindfulness having the most benefit?
Example?
- 13) How prevalent is the use of mindfulness practice with individuals with Alzheimer's disease? Examples?

Analysis of Data

The transcription of the data was analyzed using grounded theory to identify themes. Grounded theory uses inductive coding of the research (Padgett, 2008). Using inductive coding

allowed the researcher to develop the code directly from what is being said in the transcript. Grounded theory allowed the researcher to examine the transcripts and pull out themes from the data. For the purpose of this research grounded theory was chosen to allow the researcher to explore fully all aspects of how and why mindfulness may be used with AD. The themes of the research were pulled out of the transcripts by developing codes that correspond to the emerging themes of the research. The codes consisted of phrases and concepts that related to mindfulness. If a phrase was repeated that was developed into a code and also if a concept was of interest to the researcher that was also developed into a code. These codes assisted the researcher by narrowing down the themes that emerged to four themes. The researcher analyzed the themes with the literature review to examine similarities and conflicting data. The researcher looked for themes that apply to the strengths of the use of mindfulness with individuals with AD.

Because of the conceptual framework of strengths based perspective, the transcripts were first analyzed to explore the strengths of the use of mindfulness practices with people with Alzheimer's disease. All three transcripts were first reviewed as a whole and then each transcript was reviewed line by line to pull out themes from the interviews. The themes were gathered from the data by looking for patterns of repetitiveness or sameness. Other themes that were pulled out were ideas that appeared to be different to the overall picture.

Strengths and Limitations

The method for this research has strengths and limitations. The strengths would include getting a broader picture of how mindfulness may be used with individuals with AD. Examining the use of mindfulness with AD from the point of view of the professional, is also a strength as this will be new research. This is a small exploratory study on how mindfulness is used with individuals with AD. By using a qualitative design for this study this will help the researcher

better explore the question of how mindfulness practice is used with individuals with Alzheimer's disease as this is a relatively new intervention.

The limitation of this study was in the method of gathering participants. Using one professional group to gather participants from, may have been a limiting factor in recruiting participants as only one participant was discovered from the professional group. Even with expanding the search for participants to include contacting personal and professional contacts and contacting mindfulness centers did not increase the sample size greatly. The small size of the sample used was a limitation to this study. This study was only conducted in one metropolitan city in the Midwest and only contains information from one geographical location.

Results

The purpose of the research interviews was to explore how professionals working with individuals with Alzheimer's disease use mindfulness practices in their work. The three professionals that were interviewed all had different professional backgrounds, one was an art therapist, one was a recreational therapist and one had a background in human resources. One of the interviewees worked in a community setting and the other two worked in a skilled nursing home setting. All three respondents were white females who live and work in the Twin Cities area on Minnesota.

Themes

When analyzing the transcripts, four themes emerged. These themes include the use of mindfulness with AD, lowering distress and stress in individuals with AD, the stages of AD that would benefit from mindfulness, and the training and education needed on mindfulness.

Use of mindfulness with AD

One of the themes that was identified by reviewing the transcripts was the use of mindfulness in professionals to be in the moment when working with individuals with Alzheimer's disease. Two out of the three respondents talked about being in the moment.

One participant stated:

It is really beneficial if you can be in the moment with them, because to them it is really real and when you are not in the moment that is when you start to get escalation, you get disagreements, you, the world really falls apart on them.

And another stated:

I really believe that Alzheimer's people are already in the moment. They don't have the short term memory, that it is really easier for them.

The other participant used mindfulness in more of a structured setting and studied the use with people with the disease and their care partners/caregivers. They responded by stating:

There was studies done with care partners, but not anyone living with this disease. So what we did is we, (...) comparing, knowing that they are both different, an educational support group with a mindfulness group.

Lowering distress and stress

Two of the participants talk about how it is up to the staff or professional who is working with someone with Alzheimer's disease to join that person in the moment. By the staff member or professional joining in the moment, this leads to causing less distress for the individual with Alzheimer's disease.

One participant stated:

It's important especially with those with memory loss that you are really giving the subject the attention that they are looking for, because they're confused upstairs [in the brain] and if you don't address what they are doing then it almost makes the situation worse.

Another stated the following:

In a perfect world if everyone [professional staff] practiced it, I think everyone would be a lot happier. I think that the whole atmosphere would be less agitation.

Another participant talked about the benefit of using mindfulness as a way to reduce the stress that a person with Alzheimer's disease was experiencing while they were processing through the disease:

This was great when we did the study we really found that it decreased stress and this is what people said as well. (...) And if I want to jump and say that it helped with feeling sad or depressed there was, um, people had just a little bit more joy. That was part of that, but mainly the stress was what we found.

Stages of Alzheimer's Disease

Because AD is a progressive disease, as the disease progresses it is described in different stages. These stages are described in different ways. The Alzheimer's Association lists seven stages that a person with AD will go through (AA, 2015). At times the stages are simplified into three stages called mild, moderate, or severe and even early, middle, or late stages. All three of the respondents had different ideas of what stage of the disease mindfulness could be used in.

One participant talked about the earlier stages:

I would say stages one and two, as they progress into the three and four, it becomes, it's so hard because there are a million different kinds of memory loss out there too. And I would say, but in one and two that's where you're getting the most of your arguing concepts, because they are still living more in the current world where as they get deeper end of their memory loss their life becomes simpler.

Another suggested all stages:

I can see it honestly being beneficial for all stages.

While another suggested the middle stages:

I want to say more like the middle stages and even, yay, probably the middle.

Training/education in mindfulness

Only one respondent had any formal training in mindfulness.

I actually took a class last year, from a mindfulness trainer. (...) I believe the class was 1 ½ hours for eight weeks. Ah, and we had homework to do.

All three agree that mindfulness is important and that more training on this subject is needed.

One responded by stating:

I say it's something that I think more people need to be aware of that.

Another:

I wish there was more going on with that, because it is, it seems like you see yoga or tai chi, sometime, tai chi, but mindfulness it doesn't seem like there is a lot out there and maybe little pockets, but it would be great to see more because I just from experiencing it I know that it would be beneficial.

And lastly:

Unfortunately, I don't think a lot of people are aware of mindfulness. Yay, it's a thing that I think people need to be educated.

The use of mindfulness practices with individuals with AD can be used as an intervention in different ways and in different stages of AD. The research shows the benefits that mindfulness has on individuals with AD. Benefits of mindfulness are broad and can be applied to both professional staff and individuals with AD.

Discussion

This research used qualitative designed research to explore how mindfulness is used when someone has a diagnosis of Alzheimer's disease. The research interviewed professionals to explore their opinions on this topic. Since this is new research the use of a qualitative design was appropriate. Using mindfulness practice with individuals diagnosed with AD, is a new intervention that has been only researched in the last five years. The purpose of this research was to explore how mindfulness is being used with individuals with AD and if it is not being used, should it? The research looked at the benefits or potential benefits that mindfulness could have with individuals with AD.

Because this research had a small sample size, the findings of this study are not able to be generalized. All three respondents did support that use of mindfulness practice as beneficial in a couple different ways. First, the professional using mindfulness as an intervention to better communicate with an individual with AD has benefits to the person with AD. Secondly, learning mindfulness practices is also beneficial to the individual who has AD. How mindfulness practices are used with individual with AD continues to be a topic that needs to be explored further, but from this exploratory study that was conducted, learning mindfulness practices would be beneficial as both a better communication tool for the professional and also an intervention to assist the individual with AD as they progress through the disease.

Professional use of Mindfulness

How professionals are using mindfulness as an intervention to help communicate with someone diagnosed with AD is a new topic. As two out of the three people interviewed discussed, this method of using mindfulness needs to be explored further. While researching how mindfulness is used with individuals with AD, this was not discovered. A brief exploration

of this idea of using mindfulness in oneself as an intervention with AD did not find any results as it relates to AD. Some research does suggest that parents who are trained in mindfulness and use these approaches with children had less episodes of non-compliance (Singh et al. 2009). This approach as also studied with staff and caregivers of individuals with development disabilities in increasing joy and lowering aggression (Singh et al., 2003 & Singh et al., 2005). Individuals with AD and individuals with developmental disabilities are very different, but many individuals with developmental disabilities, like Down syndrome, go on to develop AD. According to the National Down Syndrome Society, 30% of individuals with Down syndrome will develop AD and that number increases to 50% at age 60 (2015).

Mindfulness and AD

One out of three people interviewed addressed the research question more directly. This participant talked about a research study that they had completed on the use of mindfulness with individuals diagnosed with AD and their care partners. The research that the participant completed supported the literature findings of how mindfulness can benefit an individual with AD with reducing stress and depression. Mindfulness can offers these benefits and can also increase individuals overall joy.

The area that none of the participants discussed in the findings, was the idea that using mindfulness can delay the onset and even improve the cognitive functioning of someone with AD. None of the participants mentioned improved cognitive functioning as a possible outcome of the use of mindfulness. Using mindfulness has the potential to delay onset of AD and also has the potential to improve cognitive functioning when someone has been diagnosed with AD and MCI (Chiesa et al., 2011 & Larouch et al., 2014). This area of potential benefit of AD does not appear to be a well-known benefit or even an idea that this improvement may result from the use

of mindfulness. More research on how mindfulness may affect cognitive functioning needs to be completed. Hopefully by conducting more research on how mindfulness may improve cognitive functioning would assist in helping to develop more mindfulness programs for individuals with AD.

Use in Social Work Practice

Based on the findings from this research, more questions need to be answered. One question that comes to mind is how prevalent or wide-spread is the use of mindfulness practice as it relates to AD? From the findings it does not appear to be a well-known intervention for AD. Using mindfulness techniques, whether it is in oneself or as an intervention, appears to have positive results, but why is it not used more as a common intervention? Looking at most of the research that was reviewed for this research paper, none of the research that speaks about using mindfulness with AD is more than five years old. Most of the research also appears to have small sample sizes. For social workers and other professionals to use this intervention on a more consistent basis, what is the criteria for how much research needs to show benefits prior to starting a particular treatment? If the research that is completed in this area continues to show the positive results from using mindfulness practices with individuals with AD, the assumption can be made that mindfulness will become a standard of practice for a social worker working with individuals with AD.

In the interviews that were conducted, none of the respondents were social workers. Why did no social workers participate in the research? This researcher does acknowledge the small sample size could be a factor, but the researcher is a social worker and has many connections with other social workers. My connections with other social workers are primarily with nursing home social workers. In nursing homes the person who is doing most of the programs and trying

new interventions are the therapeutic recreation staff, this may be a reason for the lack of social work participants in my research.

Limitation of Study

As discussed earlier the limitations to this study were many. The main limiting factors for this study was the lack of participants and that no social workers were included as a respondent. The researcher had other potential participants that did not commit to being interviewed and many others that were interested in the topic, but felt that they had no knowledge or expertise to share for this study.

While trying to find interviews for this research one organization's name kept being brought up as a place that is using mindfulness with people with AD. That organization is the University of Minnesota Center for Spirituality and Healing. This researcher was unable to make contact with mindfulness teachers at this center. For future research, University of Minnesota Center for Spirituality and Healing would be one agency to contact for ideas on the use of mindfulness practice with AD. Another resource may be the Mayo Clinic as they are completing a study on HABIT that includes some mindfulness practices. The HABIT program includes yoga in the 10 day program that focuses on individuals with MCI to help increase cognitive abilities. There may be other programs available that include mindfulness, but the two listed above were ones that this researcher had discovered while completing this research.

When reviewing the findings of this study, the researcher cautions the reader to keep in mind that the researcher, while having many years working with individuals with AD, the researcher has no training in mindfulness. The research gathered for this study, was the first time exposing the researcher to the many areas and complexities of what mindfulness may entail. The experience that the researcher has with individuals with AD is in an institutional setting, such as

a nursing home. Because of this experience, the findings of the research may reflect a lack of knowledge.

Future Research

While exploring the use of mindfulness practices with individuals with AD, the research and programs that were examined are new. More research in this area is needed. Future research may focus on different mindfulness practices and the benefits of the different methods. Mindfulness has some formal programs that are used in therapy such as MBSR, MBCT, DBT, and ACT and then some less structure interventions such as yoga, meditation, and tai chi. Future research needs to exam the benefits between these different interventions and to help determine if a more structured therapy approach or if using one intervention would have the same benefit. This future research would help social workers to determine what may be the best intervention or therapy to use for working with individuals who have been diagnosed with AD.

Implications for Practice

With continued discussions about integrated health care and continuing to look at the whole person when providing care for people, training in mindfulness practices will be necessary in the future. As there continues to be no cure for AD, social workers will need to be prepared to work with individuals with AD in creative ways. Being aware of alternative interventions that may offer some hope to individuals with AD is a must for any social worker who specializes with working with this population.

Sharing this knowledge with other individuals who are working with individuals with AD will also be necessary. Awareness of using mindfulness practices with individuals with AD needs to happen by providing trainings and outreach to professionals. This can happen in a variety of ways. One way would be to speak to the Alzheimer's Associations care consultants.

Another would be to continue to talk to other professionals about the benefits that mindfulness training can have on the lives of individuals living with AD.

Policy Considerations

The use of mindfulness as a tool for better communication with an individual with AD could have an impact on future policy. In August of 2008, the Minnesota Department of Health started to require all nursing facilities that care for individuals with AD to provide special training in AD. Part of that training includes an area on communication (Minnesota Department of Health, 2008). Mindfulness training may be an area to look at to add to how staff and professionals are taught to communicate with an individual with AD.

Other policy consideration may also include more mindfulness training as a non-pharmacological intervention when working with an individual with AD. Many individuals with a diagnosis of AD develop behaviors that are disturbing to others and/or potentially dangerous to themselves or others. When these behaviors are shown, many times a doctor will prescribed an antipsychotic medication to control these behaviors. Antipsychotic medications have harmful side effects, especially when used with the older adult population. If mindfulness can be used as a non-pharmalogical intervention by staff, harmful medications may be reduced. Currently there is a push to decrease antipsychotic medications with older adults, by requiring training in alternative non-pharmacological interventions such as mindfulness, decreasing medications may more successful.

In conclusion, the research about using mindfulness with individuals with AD shows some positive benefits, but more research needs to be done. The purpose of the research was to determine if mindfulness could offer some hope to people who have been diagnosed with AD and I believe that it does. As one of the participants stated *“people had just a little bit more joy”*

when using mindfulness as an intervention with AD. The research into using mindfulness needs to continue to explore how it is used with individuals with AD. As a social worker working with individuals with AD, finding an intervention that can give hope to some with a terminal diagnoses is critical to assisting someone as they are progressing through this disease process.

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Appendix A**CONSENT FORM**
UNIVERSITY OF ST. THOMAS**The Use of Mindfulness Practice with Alzheimer's Disease****[691948-1]**

I am conducting a study about mindfulness practice is used with individuals with Alzheimer's disease. I invite you to participate in this research. You were selected as a possible participant because you are a memory care professional who works with individuals with Alzheimer's disease and uses mindfulness strategies in your practice. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Gina Hemmesch, principle investigator, and Katharine Hill, research advisor from the school of social work.

Background Information:

The purpose of this study is: to examine how mindfulness practice is used with individuals with AD and what benefits practitioners are seeing with this practice. The research will be conducted will a qualitative study that will ask 13 questions about the use of mindfulness practice with Alzheimer's disease. This research will benefit both social workers and individuals with Alzheimer's disease.

Procedures:

If you agree to be in this study, I will ask you to do the following things: I will be asking you 13 questions about how you use mindfulness in a one-time interview that will take approximately one hour. This interview will be audio taped.

Risks and Benefits of Being in the Study:

No known risks and benefits.

Compensation:

There is no compensation for participating in this research.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include audio recordings, and transcripts will be kept on a password protected computer that the researcher will only have access to. Once the research has been presented all recordings and transcripts will be erased from the computer and any paper copies will be shredded. This consent form has been produced to insure that you understand how your participation in this research will be kept confidential. Only the principal investigator will know about your participation in this research. The signed consent form will be kept in a locked drawer that only the principal investigator has access to. The signed consent form will be kept for at least three years following the completion of the study.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until completion of the formal paper which will be by May 2015. You are also free to skip any questions I may ask. Should you decide to withdraw, data collected about you will not be included in the research. You can withdraw at any point during the interview process. If you decide to withdraw after the interview is completed, call me at the number listed below prior to May 2015.

Contacts and Questions

My name is Gina Hemmesch. You may ask any questions you have now. If you have questions later, you may contact me at XXX-XXX-XXXX. You may also contact my instructor Katharine Hill at XXX-XXX-XXXX. You may also contact the University of St. Thomas Institutional Review Board at XXX-XXX-XXXX with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I consent to be audio-taped.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix B

Asking for Participants.

Volunteers needed to participate in a research study. My name is Gina Hemmesch. I am a graduate student at St. Catherine University and the University of St. Thomas in the school of social work. For the completion of my master of social work degree, I need to complete a Clinical Research Paper. My research is on the use of mindfulness practice with individuals with Alzheimer's disease. I am looking for 10 volunteers to interview. If you are someone that uses mindfulness practice with individuals with Alzheimer's disease in your work setting, I want to interview you. If you are interested in being interviewed, please contact me at hemm1753@stthomas.edu.