Staying Connected

The Use of Encouragement for Families of Persons with Alzheimer’s Disease

An Experiential and Literature Review Paper

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Abstract

The Alzheimer’s Foundation of America defines Alzheimer’s as a progressive, degenerative disorder that attacks the brain’s nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. There has been an abundance of research on the effect of Alzheimer’s on caregivers; however, very little research has been done on the process of grief that families of Alzheimer’s patients experience, and how they stay connected as their loved ones change. This presentation and paper will look at Alzheimer’s disease, grief, coping, and lastly, one of the founding principles of Adlerian Theory, encouragement. The purpose of this presentation will be to instill hope and educate families on the power of encouragement as actionable hope.
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The Use of Encouragement for Families of Persons with Alzheimer’s Disease

Alzheimer’s is a disease of the brain which progresses through seven stages, and brings physical, cognitive, and personality changes. Later throughout of the progression of the disease individuals lose their ability to carry on conversation or respond to their environment. There are no current cures for Alzheimer’s though treatments are available to attempt to slow the progression (Alzheimer’s Association, 2013).

Effects of Alzheimer’s on Individuals, Caregivers, and Families

Because Alzheimer’s is a progressive disease, it leads to anxiety, stress, and prolonged mourning for individuals with the disease, their caregivers, and their families. When an individual experiences Alzheimer’s their esteem needs and social needs are threatened. These needs are define in Abraham Maslow’s “hierarchy of needs” Maslow 1943 (as cited in McLeod, 2007). These are basic human motivations that give individuals the ability to continue moving forward. When those needs can no longer be met, due to a debilitating disease, individuals will suffer from a lack of encouragement. As will be discussed later in this paper, effective coping strategies will be needed in order for individuals with Alzheimer’s and their families to cope effectively with the disease.

There has been a plethora of research regarding the effects of Alzheimer’s on caregivers (Cooper et al. 2008). Most notably listed are stress, and depression, as well as burnout. Caregivers of individuals with Alzheimer’s are required to put in full time care for their loved one, especially if they are still in the home. This care includes, meeting basic needs (providing food, water, shelter, and warmth, bathing, and dressing), constant supervision (to prevent unintentional wandering emotional care, transportation, and other unsafe behaviors.)
Families (notably the adult children) of persons with Alzheimer’s disease are most certainly affected by their loved one’s disease. Research shows that one of the greatest concerns is the “uncertainty in illness” (Stone & Jones, 2009). Participants of a study conducted by Stone and Jones in 2009 reported uncertainty related to possible genetic predisposition, and complex and conflicting roles in caring for an ill parent. There are also social uncertainties and medical uncertainties involved. Social uncertainty refers to the question of how their loved one will “fit in” with society and what social supports are available. Encouragement is an important part in this uncertainty as it is essential that caregivers and families continue to build up the social supports of their loved one and themselves during this great time of difficulty. Raising awareness and having discussions with those inside and outside of their social circles can lower the risk of isolation for the person with Alzheimer’s and their loved ones (Duggleby, Williams, & Bollinger, 2009). The research regarding effects of Alzheimer’s on families is minimal at best (Sanders, Ott, & Noonan, 2008). What can be postulated is that families of Alzheimer’s patients might be affected by the lack of recognition from their loved ones in the middle and late stages of the disease, the possibility of having the disease themselves, and the act of watching as their loved one gradually fades into someone they no longer know (Hodder, 2006).

As the disease continues to progress, it seems difficult to imagine how families can still feel a sense of hope and encouragement. Encouragement as Adler saw it was something that could only be found through action. Adler (as cited in Ansbacher, 1978) stated that “courage is found only on the side that advances the community.” The factors that contribute to how, when, and if a family takes action may be determined by their level of resiliency, their communication styles, and their use of family rituals.
Family Resiliency and Encouragement

Families are made up of individuals who operate under the system of the family. Resiliency is the way in which one responds to risk and crisis. Families who are resilient are likely to meet hard times with strength and come out the other side still functioning appropriately. Families who do not have much resiliency may meet crisis and fall apart. Benzies and Mychashiu (2009) studied the protective factors that contribute to family resiliency.

In relation to Alzheimer’s, families who are resilient are more likely to meet the disease head on and thrive as a family throughout the duration of the disease and beyond the loss of their loved one.

The study (Benzies & Mychashiu, 2009) focused on protective factors for the individual, family, and community. The following are the protective factors for resiliency in each category:

<table>
<thead>
<tr>
<th>Individual</th>
<th>Family</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Internal locus of control</td>
<td>• Family Structure</td>
<td>• Involvement in the community</td>
</tr>
<tr>
<td>• Emotional regulation</td>
<td>• Intimate partner relationship stability</td>
<td>• Peer acceptance</td>
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<tr>
<td>• Belief Systems</td>
<td>• Family Cohesion</td>
<td>• Supportive mentors</td>
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<td>• Self-efficacy</td>
<td>• Supportive parent-child interaction</td>
<td>• Safe neighborhoods</td>
</tr>
<tr>
<td>• Effective Coping Skills</td>
<td>• Stimulating environment</td>
<td>• Access to quality schools, child care</td>
</tr>
<tr>
<td>• Increased education, skills, and training</td>
<td>• Social support</td>
<td>• Access to quality health care</td>
</tr>
<tr>
<td>• Health</td>
<td>• Family of origin influences</td>
<td></td>
</tr>
<tr>
<td>• Temperament</td>
<td>• Stable and adequate income</td>
<td></td>
</tr>
<tr>
<td>• Gender</td>
<td>• Adequate housing</td>
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</tr>
</tbody>
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Table 1

A model for understanding this concept is the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin, Thompson, & McCubbin, 1996). This model focuses on the families’ strengths rather than deficits. Knowing what a family does well already can help the
psychotherapist working with the family have a starting point to build off of when working through the crisis/change/illness with them. The family resilience approach sees people and families capable of repair as opposed to viewing them as damaged (Huber, 2006).

Understanding family resiliency can assist psychotherapists in promoting encouragement at the right levels and knowing what type of community action is necessary to ensure the family continues to be resilient (Frain et al., 2007). As shown in Table 1 positive interactions between family members is a primary factor that contributes to resiliency

**Family Communication and Encouragement**

Communication between family members can be impacted by individual personality, relationship history, and the communication style of the family (Mancini et al., 2009). It is difficult for many people to say what they feel, however with guidance, expression of feelings can be more comfortable. Because Alzheimer’s disease involved prolonged stages of mourning, there is sense of the end of life of the individual as they were known by their loved ones (Mace & Rabins, 1999). When conducting a study on what people would most like to say to their loved at the end of life, Exline et al., 2012 assembled the following categories in decreasing order of frequency; love, praise/affirmation, gratitude/thanks, will miss you, reassurance, hanging on, letting go, see you again, forgiveness, apology, seek forgiveness, offense by family member, goodbye/farewell. The meaning of “end of life” may be different for those with Alzheimer’s disease and their families; it may be instead the stage of the disease when the individual no longer remember themselves or recognizes others.

If Alzheimer’s gives families one thing, it is some time; time to say what they need to say, to come to terms with their feelings, and to take time to enhance the relationship with the
loved one. Communication beginning in the early stages of the disease is important no matter the message.

**Family Rituals and Encouragement**

Families are often spread out in distance and in time. Family rituals are a way of bringing families together in a positive movement towards the good of the family (Wolin & Bennett, 1984). Dinkmeyer and Losoncy (1996) defined encouragement as “the process of facilitating the development of a person’s inner resources and courage towards positive movement” (p. 7). This positive movement of getting the family together on a regular and expected basis is an important part of encouragement for the family and the loved one with Alzheimer’s disease.

As was examined by Richardson (2012), family rituals are inherently important in supporting the family system and those who may be suffering within that system. “One of the main goals of ritual and ceremony is to reduce isolation and create a positive social response to the person who is suffering” (p. 75). Rituals can be identified as a plethora of things depending on religion, culture, and family history. Rituals can be weekly dinner at Grandmas, holiday celebrations, birthdays, special anniversaries, funerals, baptisms, religious healing ceremonies, cultural ceremonies, and others. These rituals may provide a sense of comfort, familiarity, and support for all member of the family system in which they operate (Imber-Black, Roberts, & Whiting, 1988).

Bossard and Boll (1950) as cited by Smit, (2006) drew attention to rituals as important role players in family functioning—being promoters of stability in daily family life as well as challenging times of strain. Rituals have meaning to family members and each member of the family has a role in it. Studies show the daily rituals for persons with Alzheimer’s disease are key to their overall functioning and the delaying of advancement through the disease. The
following is an excerpt from the web page www.alzheimerdisease.tv writing by author Gary Chandler (2014):

One recent case demonstrated the power of such rituals to bring out the best in a person. Martha was a silver-haired, 82-year-old dementia patient whose adult daughter visited her in her memory care facility every day. Usually, Martha spent most of her day asleep in bed, and when she sat in a chair, she tended to slump to one side, seemingly oblivious of her surroundings. But within a few minutes of the start of a service, she would sit straight up, look at her daughter, and join enthusiastically in the prayers and hymns. On more than one occasion she even told her daughter that she loved her.

The implicit expectation that dementia patients will somehow withdraw and shrivel up can become a self-fulfilling prophecy. Martha had been in and out of hospice three times. Three times her daughter had prepared to say goodbye to her for the last time. The key in such cases is to avoid the mentality that the most anyone can hope is that patients will simply keep quiet and leave everyone alone. As Theresa says, “We need to avoid treating the Marthas of the world as just patients we do things to. We must never forget that they are also human beings we can do things with.”

It is important for families to continue their rituals and include the family member with Alzheimer’s in those rituals. Rituals have a profound effect on the connectedness of families (Wolin & Bennet). Rituals are action. Rituals can offer a sense of relief and encouragement for families and keep them connected throughout the course of their loved one’s disease and long after.
Grief and Encouragement

Grief has long been something that researchers on Alzheimer’s did not consider when discussing the impact of stress on caregivers. Sanders and colleagues, 2008 studied grief in caregivers of persons with Alzheimer’s and related dementia. This qualitative study points out seven prominent themes: yearning for the past, regret and guilt, isolation, restricted freedom, life stressors, systemic issues, and coping strategies. Meuser and Marwit, (2001) (as cited in Sanders et al., 2008) observed the differences in grief between the spouse and the adult children of individuals with dementia through each stage of the disease. What can be postulated is that regardless of the differences, both the spouse and children would benefit from taking action towards a better outcome. Families together can join advocacy groups, communicate effectively, and share their stories (Clare, 2002).

Grief also comes with a sense of hopelessness for the individual with Alzheimer’s. In Adlerian theory, the lifestyle, or organization of how the individual understands of their world, provides the foundation for which that individual will experience grief. For example a person whose lifestyle promoted that “men are always strong and capable” will grieve their father’s cognitive and physical decline differently than someone whose lifestyle supported the belief that “men are weak and impossible” (Hartshorne, 2003). Another component of grief as studied by Adler is attachment. “The particular grief reaction can be attributed to the attachment style and to the degree of attachment in the relationship. Those with secure attachment patterns may have an easier time processing their grief while those who were avoidant may avoid the emotions of grief” (Hartshorne, 2003, p. 148).

Family members who are grieving their still living family member with Alzheimer’s may grieve and react in the same patterns. Family members who are securely attached will continue
the relationship and attempt to stay connected, while those who are avoidant will move further away from the pain and the grief of losing their loved one to the disease. In working with individuals who are avoidant, the psychotherapist can encourage the client through their therapeutic relationship and insight. “Insight involves making the counselee aware of why he chooses to function as he does. Developing in him full awareness of the element of choice can be most encouraging. The counselee may be pessimistic and discouraged about the possibility of change, so it is important that he recognize his creative capacity for interpreting his life situation and for choosing to function in a different manner” (Dinkmeyer, 1972, p. 180).

Coping Through Action

Bringing together family rituals, communication, and grief, brings to the forefront the meaning of encouragement in the way people cope with Alzheimer’s disease (Carlson & Maniacci, 2006).

A study conducted by Clare, 2002, aimed to identify and conceptualize the coping strategies used by people with early-stage Alzheimer’s disease. These strategies are important for the individual and the family as well. According to Clare, “An understanding of how people with dementia naturally attempt to adjust and cope therefore provides an important basis for developing appropriate and sensitive interventions intended to maximize self-efficacy and coping, and combats threats to self-esteem” (2002, p. 139). Coping strategies that were identified serve the needs discussed earlier and are as follows:

- Enhancing social contacts and support, and reducing isolation.
- Provided opportunities to talk about the experience and emotional impact of dementia.
- Helping people to identify and engage in activities that they can still enjoy.
- Identifying ways of being useful and making a contribution.
• Enabling people with dementia to access information that is appropriate to their needs.
• Assisting in the development of realistic and effective compensatory strategies.
• Maintaining self-concept and a sense of self-worth.

Coping can be experienced in different ways by different people, just as grief is experience differently (Papastavrou et al., 2011). Coping for caregivers and family members might include social supports, spiritual beliefs, and education on the disease (Kelley, 2012) (Rabinowitz et al., 2010).

All of the strategies listed above are tangible, actionable strategies. They all serve the purpose of encouraging the individual with Alzheimer’s and their families through the course of the disease. Social supports, shared experiences, and maintaining self-worth can be related to Adler’s concept of courage and encouragement (Carlson, Watts, & Maniaci, 2006).

Encouragement

Encouragement is the foundation of Adlerian Therapy. Encouragement does not mean to only give hope, but also to encourage others to act and contribute. In Alzheimer’s where there is little that can be done to stop the course of disease, there is so much that can be done to give hope to families, to individuals with the disease, and to the community, most of which can be done through action. The hope that comes from the knowledge that individuals are able to create positive outcomes from negative situations is powerful and can be established in support groups and individual/family therapy (Bahlman & Dinter, 2001).

Continuing to take action is important for families and caregivers of those with Alzheimer’s disease. Ideas for actionable hope include; getting involved in Alzheimer’s Foundation events, attending support groups and speaking about their experience, telling their story to through media and to their families, volunteering with the assistance of a caregiver or loved one, attending community events, and others. Not all of these things can be done when patients are in the late/final
stages of the disease, but what the loved ones can do can impact the family and future generations greatly. Sharing the story of your loved one can be one of the most therapeutic and poignant experiences for the family or spouse of a person’s with Alzheimer’s and if able, the person with Alzheimer’s could write their own story for others to add to later (Imper & Rubin, 2011).

These same courageous tasks can and should be taken on by family members as well. Each individual will have a different idea of how they can give back and contribute. Volunteering for the Alzheimer’s Foundation, participating in local events, spending time in the dementia care unit at a local nursing home, public speaking, organizing family events, caring for the loved one, joining/starting support groups, and providing supervision and transportation are only some of the ways individual can be encouraged (Stempel, 1994).

The writer believes that by giving encouragement to loved ones new doors for healing and communication are opened and opportunities for coming together are highlighted.

**Ideas for Encouragement**

- Continue Family Rituals
- Take time to cry
- Take time to reflect
- Laugh
- Be a REPRESENTATIVE
- Encourage each other
- Have the courage to take action
- Get Involved
- Create a Memory Book
- Forgive/Ask for Forgiveness
- Take advantage of the time you have
- Love unconditionally
- REMEMBER

**Be a Representative**

Following the literature review and all of the information the writer found regarding Alzheimer’s, coping, grief, and encouragement, it is the writer’s belief that families can improve the overall emotional well-being of their loved ones and themselves if they are able to foster encouragement, patience, and hold on to the memories that their loved one can no longer remember. The writer calls this act of holding the memories as being a representative. Families become representatives of the legacy of their loved one. What they say, what they remember, and what they pass on or share with others about the individual becomes that person’s identity, an identity that they never meant to lose. If families can hold on to their memories, and continue to treat the individual as a person that they love, rather than a stranger, it is the writer’s hope that said individual will feel more hopeful as will the families.

**Therapeutic Tool for Families**

In beginning of this project the writer created a therapy tool for families to use to help foster a sense of unity of the family, to gather memories of their loved one, and to encourage relationship maintenance. The questions could also act as a guide for opening up communication between family members about their loved one and the disease. Encouragement in this activity can be found through creation and reflection as a family (Sutherland, 2011).

This tool is a memory book for families. Each family member has a list of questions created specifically for the relationship they have with the individual. There are forms for
mothers, fathers, sons, daughters, in-law children, grandchildren, brothers, sisters, friends, and spouse.

The instructions are as follows; please take some time to reflect over the following questions about ___________. This project is meant to gain memories, thoughts, and feelings about our loved one that we can share with them and each other. The memories do not have to all be great, or idyllic, just real. If you prefer to add photos or create a collage you are welcome to do so. Please feel free to write or type your answers and turn them in how you would like them to appear in the book. The original copy of this book will be given to ___________ and copies will be made for all who participated. This project is created to help us remember what our loved one cannot and to keep those memories alive for them and for ourselves.

The writer’s hope for this tool is that not only will it gather information and memories for loved ones, but it would also offer each individual private time to reflect on their relationship with their loved ones, as well as their defining memories.

This tool was not presented as an actual tested therapeutic tool, rather as a suggested idea to those who might be looking for something creative, functional, and healing for individuals and families. Here are examples of questions that can found on the various forms, these questions are just leads:

Spouse/Partner Form

What is/was your partner like as a husband/wife?

What are your earliest memories of your partner?

What would you say are the most meaningful memories you created together?

Say a little about your relationship history: (meeting, marrying, struggles, joys, etc.)

What is something you hope your partner never forgets or you’d like to remind them of?
How has your partners Alzheimer’s most impacted you? How do you cope?

*Child Form*

What was your mother/father like as a parent?

Who of your siblings (if applicable) is most like your parent?

What do you most admire about your parent?

Share some memories you had with your parent. Share some struggles.

What is something you hope your parent never forgets or you’d like to remind them of?

How has your parents Alzheimer’s impacted you? How do you cope?

*Grandchild Form*

Describe your grandparent:

Share some memories of your grandparent:

What do you most admire about your grandparent?

What is something you hope your grandparent never forgets or you’d like to remind them of?

What is the hardest part of your grandparents Alzheimer’s for you? How do you deal with it?

*Sibling Form*

What is/was your sibling like as a brother/sister?

What are your earliest memories of your sibling?

What would you say are the most meaningful memories you created together?

What is something you hope your sibling never forgets or you’d like to remind them of?

How has your partners Alzheimer’s most impacted you? How do you cope?

*Friend Form*

Describe your friend?

What are your earliest memories of your friend?
What would you say are the most meaningful memories you created together?

What is something you hope your friend never forgets or you’d like to remind them of?

How has your friend’s Alzheimer’s most impacted you? How do you cope?

The simple act of creating something can spark a therapeutic moment for families. “Art amplifies human expression and relationships. It has the capacity to speak to us through parables, metaphors, or documentary narratives that might otherwise be only vaguely accessible” (Main & Boughner p. 284).

Presentation Summary

For this project, the writer spoke to a support group of caregivers and family members of persons with Alzheimer’s disease. The presentation consisted of general information on the topics family communication, resiliency, rituals, grief and coping. Encouragement in the form of actionable hope, and sharing memories were the highlight of the presentation. During the presentation a therapeutic tool was presented as an idea for families struggling with Alzheimer’s. This tool is discussed in depth above. The information presented was reflective of literature that was reviewed for this project, as well as the combination of theory and background the author has gathered in class and working with individuals and families. The support group set up allowed for family members to speak throughout the presentation and add their personal experiences to the information being presented. The writer was able to share their personal experiences with the impact of Alzheimer’s disease as well as answer questions on how to implement actionable hope.

This type of presentation was created for and would be most valuable to family members and family caregivers of individuals suffering from Alzheimer’s or dementia. It is meant to offer brief education, encouragement, hope, and to foster a sense of control over one’s experience with
the disease. The presentation also aims to offer families additional ways of viewing the disease and its impact on their relationships with the identified individual.

There are limitations to this presentation. The greatest limitation appears to be the lack of research in how encouragement fosters hope for individuals with Alzheimer’s or their families specifically, as well as how encouragement works for those who do not have adequate cognitive capabilities.

The author gave this presentation and found that those who attended were responsive to the information and stated that the tools and encouragement given was helpful. Those in attendance felt that the personal touch of the presentation was beneficial to them in connecting with the materials, and many had questions following the support group about how to get involved.

**Conclusion**

Alzheimer’s is a progressive disorder that results in loss of memory, changes in thinking skills, and behavioral changes. The impact of the disease on families has not been widely researched, however, aspects of family communication, resiliency, rituals, coping, grief, and encouragement all offer insight and hope to those families.

Through review of the literature on Alzheimer’s it has been shown that families and caregivers face challenges related to the uncertainty of the illness, and the trials that the disease presents.

Family resiliency is one component of how families respond to Alzheimer’s disease and the overall impact it has on the family. Resiliency can be determined by a number of things. Knowledge of the protective factors of families can help increase the understanding of how resilient the family will be during and after the disease has run its course.
Having time to share thoughts and feelings with loved ones is an aspect of Alzheimer’s that hasn’t been researched in depth, however, the categories that people would most like to communicate to their loved ones prior to the end of life has been studied and would be an applicable discussion for families of Alzheimer’s patients. Alzheimer’s takes memories away and families have the opportunity to share with their loved one prior to the complete onset of the disease.

Rituals are profoundly important to Alzheimer’s patients in their daily life as well as with their family. The study of family rituals has indicated that families with rituals that are maintained provide support and comfort for each other, as the rituals are common and the role of the individual is familiar.

Grief in Alzheimer’s is complex. Spouses and families grieve for long periods of time as they slowly lose their loved one. Grief is expressed differently by individuals based on a variety of factors, one of which is their lifestyle. A person’s lifestyle explains the way they view the world i.e. men and women’s roles in the family.

Coping strategies are important for all people regardless of what challenges they face. A list of coping skills was identified in the reviewed literature (Clare, 2002, p. 146):

- Enhancing social contacts and support, and reducing isolation.
- Provided opportunities to talk about the experience and emotional impact of dementia.
- Helping people to identify and engage in activities that they can still enjoy.
- Identifying ways of being useful and making a contribution.
- Enabling people with dementia to access information that is appropriate to their needs.
- Assisting in the development of realistic and effective compensatory strategies.
Encouragement is perhaps the most important piece of this project. The author has postulated that encouragement can strongly impact the families of those with Alzheimer’s disease in a positive way. Giving individuals and families the courage to take action against the disease in a constructive manner allows them to take control over the memories they cherish.

Alongside encouragement is the author’s idea of being a representative. Being a representative means that the individual is taking ownership over the memories of their loved one. They are writing them down, they are sharing stories, they are creating new memories, and they are cataloging those things. A representative can make an impact by simply being themselves around their loved one, even if they are not recognized as such. Having a conversation despite the pain it causes, in an effort to give comfort to their loved one is selfless and encouraging.

A memory book tool was created by the author as an idea for families to remember their loved ones in a way that is real and honest and to have a place to keep those memories alive for the entire family.

Families of Alzheimer’s patients have a difficult road of grief, pain, and challenge to navigate. The hope for the future is that families can gain a sense of encouragement, hope, and peace in the face of this difficult disease.
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