

Thanksgiving: A Reflection on Personal and Professional Caregiving with Alzheimer's

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Abstract: Alzheimer's disease (AD) slowly debilitates those who experience it and shifts people, usually family members, into the role of caregivers. Professional caregivers will have to become increasingly skilled in responding to Alzheimer's disease to meet the needs of both the person with AD and family caregivers, as supporting family caregivers can result in increased well-being for the person with AD and delay in the use of higher levels of care. Personal reflections about serving as both a family caregiver and a professional caregiver to persons with Alzheimer's disease are used to think about how to improve and enhance professional caregiving when working with family caregivers of persons with Alzheimer's disease.

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Thanksgiving nears. My to do list: (1) get turkey and groceries, (2) make sure table cloth is clean, (3) prepare guest room, and (4) get Dad to take a bath. In the previous year, Dad was bathing less and less, as shown through his appearance and odor. Mom was tiring of negotiating this with him. She would point out the need; he would deny it. Arguments of logic always failed since he truly believed that he had "just bathed the other day." She began the campaign to get him to shower two weeks before the holiday. By the end of the first week, she concluded she should stop. Bathing was getting tied up in his asserting control over his narrowing world. She was often the target of his frustration and anger when asked to do daily activities, and she needed to save her influence to assure he took his medication. She was very stressed by this "new" symptom. The more he refused, the greater her stress. This symptom crept up over the years, just like so many others did. First, he dropped from daily showers to a few times per week. Then it was about once a week. Now it was every several weeks and only with much urging. During the summer, a couple of times when I talked to Dad, it resulted in his showering the following day. In early fall, I would leave notes on his bathroom mirror to remind him. That was only sort of successful once or twice. So for Thanksgiving, I told Mom I would take care of it. Over the weekend before the holiday, I placed a reminder note on the mirror, "Shower before church." No success. I tried to ask him questions which provided him some control and could result in what he needed. "Will you be taking your shower and shaving on Monday or Tuesday morning?" He answered, "Tuesday," and promptly forgot; he did not take the shower on Tuesday. Then I moved to desperation. I used an approach that had little

chance of succeeding; I laid down an ultimatum. "Dad, if you want to join us for Thanksgiving, you have to bathe and change clothes before I pick you and Mom up on Thursday." I woke up Thanksgiving morning, got the bird in the oven and then headed to pick up my parents for the day. Mom was ready and waiting. Dad had not showered in nearly a month; he and Mom had argued before I arrived. The scene was unpleasant and sad. Kind requests, cajoling, logic, ultimatums, nothing worked. "Dad, I will wait; simply shower now. It will take 30 minutes." "Dad, we have other guests coming, and you have an odor; a quick shower can take care of it." "Really, you would rather stay here all day by yourself than be with family just to skip a shower?" "Dad, it would mean a lot to me if you would simply do this and join us for the holiday." Neither Mom nor I succeeded in using our knowledge of Alzheimer's disease that day to help Dad or ourselves. She was angry, and I became very upset. Through tears, I kept my ultimatum. He did not join us for Thanksgiving dinner. Mom came without him. I tried to shake off the sadness and anger I felt with the disease to enjoy the day. Mom did the same. When I took Mom home that evening, Dad was watching television. He said he had a good day and asked us about ours as if we had been out doing errands. He had no sense of how long we had been gone. He did not recall the morning arguments. He had not been upset for long. He did not think he had missed anything; we did. On Friday morning, he awakened and took a shower.

Our family's story of Alzheimer's disease (AD) is like many families' stories. What is different is that I am a geriatric social worker who worked extensively with persons who have AD and their families. Alzheimer's has been with me from birth. As a new baby, my

grandmother, who had what would probably be diagnosed today as early onset Alzheimer's, confused me with my mother, thinking I was her daughter rather than her granddaughter. She refused to give me back to Mom for care. This scared everyone. She lived with the disease another 10 years. As a new social worker, I took a job at a long term care facility and worked extensively with persons who have Alzheimer's and their families. Later, I worked with community dwelling seniors, some of whom were early in their experience of dementia. For the past 10 years, I have been teaching social work students about Alzheimer's – how to assist persons with the disease and their families. Because families provide the bulk of care, Alzheimer's is a family disease (Alzheimer's Association, 2010; Brodaty & Donkin, 2009). Therefore, professionals need to be prepared to assist them. Since early adulthood, I knew I would one day become a family caregiver. I expected it to be for Mom because of my grandmother's AD. However, I was an adult child caregiver of a father with AD and am the niece of two uncles and an aunt with the disease.

I thought my wealth of professional experience, would make our family somehow weather the storm of AD more successfully. The Thanksgiving ultimatum clearly shows it has not. Knowing what works for many people does not always translate into success, and personal emotions get in the way. I have struggled with and am letting go of my embarrassment and disappointment that I am not the superstar caregiver I thought I could be. Pain, frustration, absurdity, joy, and sadness provide powerful new insights about caregiving. Naturally, I find myself musing and reflecting upon my years of practice with persons who have AD and their families through the lens of being the family member. For the most part, the reflection is reassuring. I generally performed well, in ways which were supportive to most families. However, I would do some things differently in hindsight. Using my family's journey into AD and my own experience as an adult child caregiver, this article will reflect on helping the families of persons with AD. As a bit of background, Mom is still living; Dad died earlier this year. I have three fantastic siblings and husband who share this story. I sought everyone's permission to write this prior to Dad's death, and they have provided valuable feedback.

What is Really Going On?

The exact date of diagnosis of AD is not clear. In the mid-1990s, my father had a stroke, a subarachnoid hemorrhage to be exact. It occurred just weeks prior to my daughter's birth, his first grandchild. He made a remarkable recovery physically and returned to work; however, memories for periods of our shared family history were gone. We would discover this when Mom, our family memory keeper, would say something at family events. He would reply, "Did that really happen? I don't recall it." Due to his family's history of heart disease and diabetes, all focus was on the cardiac and vascular systems and prevention of further strokes. However, quietly in the background, something else was happening. In hindsight, we can see that he began to struggle at work and at home much sooner than anyone said "Alzheimer's." He worked past typical retirement age. By the mid-2000s, he was increasingly irritated with coworkers and employees. This was unlike him. He retired when forced by company reorganization. Always brilliant with numbers, he took a part-time retirement job in tax preparation (something he could easily do). That did not work out either. He explained everything away outside himself, saying things like, "These tax companies are just taking advantage of poor people by keeping so much of their refunds. This is a racket, so I quit." We all agreed to his perception of reality, especially his social worker daughter. Looking back, he may not have been able to do the job well, and his stories, even if partially true, were probably ways to cover. The official diagnosis did not come until years later when he was referred to a neurologist for Parkinson's symptoms.

Dad's experience is fairly common. Persons with AD often experience a "lag time of a decade or more" between the disease changing the brain and clinically showing symptoms (Sperling et al., 2011, p. 282). Then there is an additional lag between symptoms and diagnosis for many. The person and the family often look for other explanations because those are more acceptable and/or treatable than AD (Reed & Bluethmann, 2008). Who wants this diagnosis? Diagnosis can be difficult because of the presence of other conditions (Shigeta & Homma, 2007). Moreover, the National Institute on Aging (n.d.) reports that autopsy research shows the majority of persons who die with an AD diagnosis also have signs of vascular disease. As a community social worker, I

was familiar with such changes in my clients. I often had my “radar” on looking for signs of cognitive change. When I noticed something, I would strongly encourage clients to see their medical doctor and ask to involve their families if they were not already involved. Frequently, people would delay seeing the doctor because they were frightened or did not want the diagnosis. I would use empathic and reflective communication skills to keep the dialogue going. I understood that it was a process to come to terms with the possibility of this diagnosis. The work would involve talking to them about the “curable” forms of dementia or the forms which can be slowed or stopped. Today, I encourage my students to also think about using motivational interviewing skills with a family early in the disease, since they are contemplating or adapting to the diagnosis (Miller & Rollnick, 2013).

Diversion and Deception, Not Reason

Some people with AD have awareness of what is happening to them and articulate it; they use it to cope (Reed & Bluethmann, 2008), at least for a while. I recall working with one person who was able to hold onto his diagnosis and utilize it well into the middle stages of the illness. He would accompany me as I moved through the care facility. When we got into the elevator or encountered someone in the hallway, he would say, “Hi, my name is Joe. What’s yours? But you should know I won’t remember it because I have Alzheimer’s.” I was always amazed by the grace of this. Most of the people with whom I worked experienced far more struggle, like Dad. Dad did not have that insight. He always tried to hide or cover the lapses, even when he was somewhat aware of them. He clung to the other diagnoses. As the disease progressed, he had moments like the Thanksgiving story where the lack of insight coupled with a lifelong stubborn streak made it impossible to do ordinary care. This was tremendously difficult because, over time, reasonable arguments and conversations went nowhere. Like other people with AD, the lack of insight impacted many facets of living including health and safety issues like bathing, taking medicine, and driving (NIA, 2010; Reed & Bluethmann, 2008). The logic trap sounds something like this:

Dad: I need to go to the store, where are my car keys? *Me:* I don’t know (a lie). You lost them (truth); haven’t you found them? *Dad:* No. *Me:* I can drive you; where do you want to go? *Dad:* I don’t need you to take me. *Me:* The doctor said you shouldn’t drive. *Dad:* No he didn’t. *Me:* Yes, he advised you shouldn’t drive because you could get lost and your reaction time is slow. *Dad:* He never said that. I am perfectly fine. I have been driving for more years than he has been alive. He just wants to stop the old guys.

I could remind him he has Alzheimer’s disease, and he would deny it, maybe get angry. I could keep using reason; it would not work. We would both become frustrated.

Because of my years of experience, I know distraction is the better approach. I could say, “Oh, by the way did you hear about . . .” and divert his attention from the thing he cannot do (driving) and allow the forgetting part of the disease to help. Early on, I fell into the logic trap anyway. I had to learn to avoid it like almost all other caregivers. I wanted him to be himself as he once was. I did not want to divert, actively lie, or lie by omission. It felt disrespectful, undignified. He just couldn’t hold onto the information and use it. We were upsetting him, often unnecessarily. We were also upsetting ourselves.

The logic trap and diversion were frequent conversations in my practice with families. I would explain that the degree of insight is related to the parts of the brain being impacted by the disease. However, intellectually understanding that the brain is misfiring, while helpful, does not always translate into emotional or behavioral understanding for family members. It is one thing to know this; it is another thing to change the patterns of interaction. In retrospect, I think I overly relied on psychoeducation and, to a lesser degree, modeling as intervention techniques (Brodsky & Donkin, 2009). Information may spur change but actually seeing professionals use a technique may be more beneficial. I wish I had used more role playing to help people build skills when families were struggling with diversion.

Additionally, I often talked with families about deception. Many family members begin to be deceptive because usual ways of interacting fail (Blum, 1994), and it just happens in a moment of

need. They blunder into it. Many family caregivers report feeling guilty or dishonest when they tell either white lies or lies of omission to the person with AD, and they may engage in it with other members of the family (Blum, 1994). Collusion may be new to them. They often share this behavior with professionals or other caregivers to gain sanction for it (Blum, 1994). I always advised families to be truthful initially to show dignity and respect to the person and to give the person the chance to use information. When families reported that conversations were devolving into arguments, that the person could not use the information, and the interactions were upsetting everyone, I coached caregivers to let many misperceptions stay (NASW, 2010). If the person said, "I had eggs for breakfast," when it was cereal, I coached to let it stand. Why have that argument; why communicate that the person misremembers? The person's misperception allows saving face. Maybe it helps to prevent depression. I coached changing topics or starting new activities. If the person wanted to do something unsafe and could not be diverted, then a lie might help. One son disconnected the stove so his mom couldn't cook. He would tell her "it wasn't working," and they needed to look into that. He never told her that he knew why it wasn't working. I advised against wholesale untruths as you never knew when the neurons were going to send a clear message, and the caregiver would be caught in it.

Even though, I knew about deceptions, understood their role in AD care, and validated their use, it upset me when I told the first white lie. On a four hour drive to the beach with just Dad in his car, he was not regulating speed well and floating into the other lane a bit too often. "Dad, you know after my long plane ride, I would really just love to be the driver, would you mind?" I lied; I would have preferred to rest. I drove the rest of the way. Driving is the topic around which I lied most often because of the safety implications for Dad and the public at large. It was also incredibly symbolic of his loss of freedom and independence related to the disease (Reed & Bluethmann, 2008). It felt as if I was somehow compromising my integrity and disrespecting him simultaneously. On the other hand, the cruelty of giving him information that he could not use or would distress him seemed equally unethical. Working with families now, the advice would not change. My attention to their emotional state in

deception would increase. I might preemptively bring up the topic of deception instead of waiting for them to raise it. An open exploration of deception juxtaposed with the alternative outcomes could lead to caregivers validating themselves.

Burden and Isolation

An interesting dance began between Mom and Dad. He was desperately trying to hold onto what he could do. Mom was trying to let him. Self-determination and control take a terrible hit as this disease progresses (Lynn, Marson, Odenheimer, & Post, 1996). My siblings and I were trying to support them, especially Mom as she was living it every day, and it was taking an emotional toll on her. Just as in the opening narrative about Thanksgiving, she bore most of the challenges of his care. My siblings and I were working and raising families. Initially, we lived in different states. Long distance caregivers make up 9% of caregivers of persons with AD (Alzheimer's Association, 2010). When they lived at a distance, I didn't call as often as I "should have." I felt guilty about it, especially since I knew what the disease was like from my professional life. It was difficult to have conversations, and doing so validated that I was losing part of Dad. Also, Mom "didn't want to burden [her] children" and didn't always share everything with us. The repetitive conversations, Dad's frustrated outbursts, his driving, and the silence became a challenge for her. He stopped playing bridge and stopped golfing. As his world got smaller, she became more and more important in it. This loss of social connections and increasing reliance on one caregiver, often a spouse, is very common (Mittelman, 2013). This places the caregiver at risk for health and mental health concerns (Mittelman, 2013). Studies estimate that between 23% to 85% of caregivers experience depression, and 16% to 45% experience anxiety (Brodsky & Donkin, 2009). Additionally, as the care takes on a bigger and bigger role, the caregiver loses contact with his/her social connections (Brodsky & Donkin, 2009). We would encourage Mom to do what she enjoyed, but she "felt guilty" leaving Dad behind. She felt saddened by the way "he was robbed of many of life's joys one at a time." Yet, like most caregivers, she continued. Mom's devotion and love for Dad was amazing to see. In a strange way, their love was never more visible.

People continue providing difficult care for a variety of reasons, including “sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures, or in rare instances greed” (Brodaty & Donkin, 2009, p. 218). I have encountered many people who care with love, respect, and reciprocity mixed with grief, sadness, and struggle. In practice, I found myself reframing choices as care when caregivers saw their decisions as failures (NASW, 2010). I provided a lot of psychoeducation about ways to provide care and service options, particularly both informal and formal respite (NASW, 2010; Brodaty & Donkin, 2009). I frequently gave caregivers permission to remain in or re-engage in important activities. I found myself engaging in self-talk: “Taking time out of the day to swim will keep me sane.” I also found myself coaching Mom. As I train professionals, I emphasize the need to encourage caregivers to care for themselves, to stay engaged in their passions. Many caregivers say that it is “selfish” to do what they like or not “fair” to the person with AD. As professionals, we can use and/or develop social networks with caregivers (Tracy & Brown, 2011), particularly those in the “life world” rather than in the service world (Condeluci, 2002). While I tried to do this, helping people reconnect to the life world was more time consuming than using formal services. Sometimes, I defaulted to the easier route due to time pressures. I encourage my students to be steadfast in spending that time because using the life world tends to be a more lasting solution and is marked by greater reciprocity, something which is very important to people when they have to receive help over a long period of time. Additionally, it is helpful to use cognitive techniques, like cognitive restructuring to shift caregivers’ perceptions (NASW, 2010; Wright, Basco, & Thase, 2006). For example, the professional might ask the caregiver what she would say to a friend who has similar circumstances. Often, caregivers will say they would encourage their friends to take care of themselves and can begin to give themselves permission. Such techniques can be used in briefer interactions, outside therapy. The professional can be therapeutic without being the therapist.

At this point in care, professional services may be helpful to families too. One theory about whether a family will use formal services is the degree to which that service provides for tasks that do not fit

caregivers’ expectations for what they should be doing (Montgomery, Rowe, & Kosloski, 2007). Our family has tried to engage formal caregivers at various points. Mom and Dad usually agreed after trying to accomplish something on their own first. They were never pre-emptive, even when encouraged. First, they hired a housekeeper and someone to mow the lawn. That required a lot of accommodation on their part as those helpers didn’t quite do things the way they did. They have used Medicare funded home health and rehab services after hospital stays. That is relatively short-lived and does not address the AD; it addresses something else. They have paid for hourly, private in-home care including assistance with bathing, shopping, and transportation. When Mom had a four month hospital and rehabilitation stay, we hired an aide to provide daily transportation and supervision so Dad could see her. They have used other formal transportation services (very expensive) as well as paying people they know to drive them. Dad had a tendency to “fire” helpers because he did not believe he needed help. Mom took to telling him that he could not fire them because they worked for her. When working with agencies, there was a lot of energy needed to get to know staff, and staff needed to get to know them. Plus, agencies often sent different people even as they were committed to trying to send the same person. This constant change is very hard for a person with AD. I heard this complaint from families when I worked with them. By contrast, if a family hires someone privately and that person becomes ill, there is no guaranteed back up. We wanted to use adult day services at one point, but could not find services which were feasible and available when needed.

For families, there is a lot of emotional and instrumental work associated with using professional care. They must use due diligence and check out the provider. They have to form relationships. Because the person with AD is not a great reporter, there is vulnerability. Often engaging professional services occurs when the family is in crisis. They are stretched thin, and asking them to do one more care-related activity may not be all that helpful. In our case, I knew what questions to ask. I knew the scope of services which might be available. That did not mean I had the time to do all the work that was necessary. On more than one occasion, discharge planners really were not offering choices. I had to ask to keep my parents with agencies where they already had

relationships. On other occasions, we were handed resource lists and told to call and see what we could arrange. Thinking back to my practice, I could have improved my performance. These insights would make me more skilled knowing when to “do for” versus when to allow families to “do things on their own” (Longhofer, Kubeck, & Floersch, 2010). I am also more cognizant of the ethical challenge of balancing provision of choice (self-determination) and information (informed consent) with the potential for both to overwhelm the caregiver. Without the needed support and guidance on using professional helpers, we may not be helping at all (best interests of the client) (NASW, 2008). Professionals make referrals all the time and forget how complex it is to seek services. Keeping that in the forefront would have helped my practice.

See Me: I Am a Caregiver

In time, Mom’s health began to fail, and her world got smaller too. As she moved through different levels of medical care, I remained consistently amazed at the lack of assessment or insight with regard to her status as a caregiver, particularly in acute care. During an unexpected hospital stay for Mom while they lived at some distance, I inquired about the discharge plan only to hear the hospital would send a home health nurse to check on Mom. I spoke by phone to the discharge planner (DP):

DP: Well, I asked them what they needed, and they said they were fine. Your dad was there, and we will give discharge instructions to both of them. *Me:* Did you inquire about the layout of the house? *DP:* No, why? *Me:* It is two stories, and the full bath is on the 2nd floor. Did you check on whether Dad could recall or carry out discharge plans? *DP:* He seemed to understand. *Me:* He has Alzheimer’s. Did you explore how Mom and Dad functioned prior to the hospitalization? *DP:* They said they were fine. *Me:* I don’t think this plan will work, would you like to know why?

It was not the first time I have silently asked, “What would happen if they did not have a social worker for a daughter?” My siblings are all smart, and they would figure out how to navigate these systems. Like many family caregivers, they have become excellent medical advocates by necessity. Almost

no one asked Mom how being the caregiver of a person with AD was impacting her health and the choices she was making. As recently as a year ago, she delayed going to the emergency room because she was unsure of who would care for Dad and because she didn’t want me to take time away from work. The result of her decision was a more protracted pneumonia and post-hospital rehab stay.

In the past seven years, I do not think any of us (mom, me, or my siblings) have ever been formally assessed for caregiver burden by anyone. Mom’s primary care physician and pulmonologist have both acknowledged the impact of being a caregiver on her health. Dad’s neurologist may have too. They did not then go on to recommend caregiver interventions, support, or other services. This is not uncommon as the professional community still does not know how to effectively target services or when to offer them so they are most likely to be used (Montgomery, et al., 2007). The one time I felt my burden was recognized (though not assessed) occurred when Dad was receiving respite care in a personal care home. The admissions person acknowledged it, perhaps because I was so tired, frazzled, and desperate in my competing roles as daughter/caregiver, mother, wife, and employee that she had no choice. Then a couple of the aides and nurses caring for Dad routinely checked on me. I found relief knowing that some professional in the complex healthcare web understood that this was tearing me apart and exhausting me. While I do not necessarily expect professionals to formally assess a secondary caregiver like me, I do expect them to assess Mom. With my parents, I am a daughter first; recommendations that I made based on my past professional life don’t carry the weight they carry when made by the treating professionals. I have often wondered why interventions were not offered. Was it that the providers were oblivious? Did the providers not know what to offer or how to offer interventions? Did the providers assume our family could handle AD because of my profession? Had professionals suggested services at an earlier point, would outcomes have been different?

Professionally, I usually met families after acute care stays because a hospitalization caused them to decide to use assisted living or nursing care. They shared stories about how the hospital did not seem to look at the whole picture for a caregiving spouse. They would comment, “My dad [caregiver] just put mom [person

with AD] first and didn't take care of himself. The hospital staff talks to him about taking care of himself and makes no mention of mom. Now we don't have any options but to use residential care because we cannot be there and don't have the money to hire someone to be there. Plus, we have two parents who need care now." I believe I did a pretty good job in checking with many family members about the impact of the caregiving and the disease on their well-being. I did not, however, often use a formal tool to assess it. In hindsight, I might add a tool like the Caregiver Strain Index (Robinson, 1983), particularly to identify people who appear "together" but may be struggling silently. When families decided to use residential care as part of the care plan, I always emphasized that people were not giving up a caregiving role but sharing it with others. I used reframing techniques and psychoeducation to support them (Montgomery, et al., 2007; NASW, 2010). I also recommended social support, like support groups (Mandell & Green, 2011; Brodaty & Donkin, 2009). I routinely screened for depression in family caregivers and referred to therapy services. I typically did not use the formal screening tools as their length sometimes irritated clients' families.

However, brief depression screening tools which have achieved greater use today, like the PHQ-9 make a consistent, formal screening easier to do (Kroenke, Spitzer, & Williams, 2001). In my teaching, I encourage health care and gerontology students to complete psychosocial assessments for aging spouses and determine if they are caregivers. They need to check in on individual burden, as well as how that is shared by understanding the full support cast (children, grandchildren, siblings, friends and neighbors) who help people to cope with this disease. Interventions directed at caregivers to decrease both emotional and physical burdens of care have demonstrated an ability to delay use of residential long-term care services (Brodaty & Donkin, 2009). Families and persons with AD appreciate that. In my case, just asking about burden without intervention was perceived as helpful, and knowing that I can rely on social support from other family, colleagues, and friends has helped. Social support potentially mitigates some of the negative health, mental health, and financial outcomes which caregivers experience (Montgomery, et al., 2007). Professionals can start by asking, responding

empathically, and supporting use of social support networks.

Grief

I recall watching my first NCAA basketball games with Dad as child. Once, quizzing him about the colors for each school in the tournament, my sister picked winners entirely based upon colors and won our family pool. As a child, a couple of times his team (so my team) was an upset tournament winner. These are warm, fond memories for me. Discussion of the season and the tournament used to delight him. Watching the games used to delight him. When Dad's alma mater got a bid in the most recent tournament, we discussed it; he was generally conversational but vague because he could not recall anything about the season or who was on the team. I was not sure if he even recalled college. As we talked, I kept an upbeat, energetic tone, and I quietly noted my sadness. For all of us, there were multiple moments per week which reminded us of who he was. Family events like baptisms or holidays presented even bigger reminders. We grieved. I watched my daughter, a young adult in the midst of creating her future, struggle with how to relate to her grandfather. She, unlike her much younger cousins, had the memory of who he has been and found it "depressing" to watch the disease take its toll. Her younger cousins, on the other hand, simply knew him like this; they did not really see who he was. As they grow up, they may develop grief as they realize they missed out on something too.

Anticipatory grief (in big moments and small ones), marks the lives of the family and the person with disease while he/she has insight (Osman, 2006). Much of the work I did with families of persons with AD was to help them voice and respond to their grief. This is a necessary part of helping the caregiver to provide care. Again, my practice was generally on target. My new understanding of it might make me slightly more empathic today. Social support from family or others living with the disease can be very effective for coping with the grief (Montgomery, et al., 2007). I often provided psychoeducation about grieving and normalization of the experience (NASW, 2010). Today, I would collect information on important family dates as well as family holidays to help caregivers prepare for them. Those preparations might involve strategies to help caregivers modify the circumstances to increase the success of including the

person with AD in family events and cognitive restructuring to shift expectations (NASW, 2010). I could have been more attentive to the multigenerational impact of the grief than I once was. When family members raised it as an issue, I addressed it. I would probably be more proactive in raising it as an issue now. While working, I recognized the difference in the staff relationships to the person with AD and the family's relationships. Professionals, even in residential settings, meet the person as he/she is today. They do not bring in the memories which create the grief. However, over time, staff will actually see loss and may grieve too. When I trained staff in how to provide dementia care, I provided instruction and support to colleagues so that they could acknowledge families' and their own grief. As I train professionals today, I try to emphasize grief and how they might respond to it.

Countertransference

A movie came out which prominently featured Alzheimer's in the plot. My siblings and I talked about whether we would go see the movie. We were all curious. We were unsure whether we wanted to see our daily life as entertainment. I think we all passed on that movie. . . maybe someday. I believe that my family's experience with AD, has strengthened me as a professional and allowed me to be more effective with families, giving me additional insight and empathy. My experience also holds the potential to do harm if I generalize my experience to others or burnout with its burden. I know that I could not do daily clinical work today with persons who have AD and their families. The potential for countertransference would be too great. Plus, I am not sure if I have the energy to maintain the professional boundary. I suspect the work would impact my personal life. I am grateful for the ability to see this and the option to do other meaningful work connected to AD without doing direct care. I anticipate I will do direct work, beyond my own family, again in the future.

Given the prevalence of AD, it is likely that many professional caregivers are also family caregivers. Clinical teams today need to find ways to support colleagues so that they can continue to care for AD in both settings. Utilization of periodic case reviews and strong supervision to check for

countertransference, as well as to look at strengths and challenges associated with the work would be beneficial and is consistent with NASW's (2010) *Standards for Social Work Practice with Family Caregivers of Older Adults*. Moreover, while the potential for countertransference is acknowledged (Kane, 2002; Genevay & Katz, 1990), we know little of its prevalence or impact in AD care across the professions. There is an opportunity for qualitative research to better understand its impact and how to manage it.

Grace and Being in the Moment

In his last years, Dad had almost no insight into the cognitive or physical, impact of the AD. During one of Mom's hospitalizations, we had to rely upon residential respite care to assure Dad's safety. He phoned all of us multiple times one evening. He had more confusion and was more easily frustrated in the evening, as is the case for many persons with AD (Mandell & Green, 2011). This is sometimes referred to as sun downing. Plus, he was outside his regular environment and routine which often increases confusion for persons with AD (Mandell & Green, 2011). The phone calls were heart breaking. He knew something was wrong. "Beth, did you know Mom is in the hospital? I need to get back home to find her. I am in this hotel here in New Jersey, and I can't find the car or my keys. I need to get to the airport. I don't have enough money or the phone number to call a cab." He was frightened and scared. The more fear he had, the less his brain could work. When asked where home was, he answered the town of his birth – a place he had not lived for fifty years and never with Mom. No amount of reassurance could settle him. I ended up on the phone with my sister and brother in tears. That night we relied on the respite staff and sleep to help him. I took comfort in knowing he would not recall his distress the next day, maybe not even in an hour. If there is one grace in Alzheimer's disease, he had absolutely no recollection of his distress or disruptive behaviors once he was diverted from them or slept. The disease, while cruel, at least spared him that indignity. This lack of remembering created a buffer for him. While it frustrated me to no end, it protected him. That is the grace.

Unlike anything else in my life, Alzheimer's has made me keenly aware of the current moment. As the disease progressed, this moment – the here-and-now –

was what Dad had. He could not recall many moments before, and he really could not project into the future. Therefore, this moment is what I had with him, letting go of my past and future focuses. I consciously tried to offer little pieces of life which he could enjoy. If that meant looking at a photo that he had seen many times but seemed completely new to him or watching a television show repeatedly because it gave him joy, I could do that. That did not mean that I gave up getting him to bathe or exercise; he still needed to do both, and they remained a struggle. I just focused on creating more good moments than not.

While in practice, I did a lot of work both with families and the rest of the care team promoting the idea that our job was to create the best “now” we could. If the care team, including the family, could string together enough good moments each day amidst the struggles, we could provide quality of life. It is perhaps not the quality of life the person once had, but it could have meaning, dignity, and moments of joy. I also did a lot of cognitive work in helping caregivers to shift their perceptions of moments so they could find little joys themselves (NASW, 2010). In a world and care system focused on cure with a disease that has no cure, this perspective might have some power to draw professionals and keep them engaged.

Giving Thanks

Returning to the earlier Thanksgiving story, it turns out there was much for which to be thankful. Initially, I had a mismatch between my expectations of what I “should” be able to do as a caregiver and what I could do. Reflection illustrates that my career has indeed helped me and, I hope, my family. I knew the tools; I just needed to start using them. I relied often on (1) self-talk, (2) reframing, (3) exercise, (4) interests, (5) talking to Mom, my husband, and my siblings, (6) laughing at the absurdity of it all, (7) learning more about the disease and caregiving, and (8) the occasional good cry (I believe crying is an incredibly wonderful way to release sad and negative emotions from time to time). I am thankful for the moments with Dad and Mom, for family support, that I could share the load, for the colleagues (past and present) who have taught me and supported me, and for all the persons with AD and their families who allowed me to share

a part of their journey. I hope that our family efforts will show my daughter and her cousins how to take care of each other when life presents difficult challenges and how to stay connected in a caring way even if we frustrate one another. I hope my professional reflections will help other professionals have a few additional ideas about how to assess and intervene when they meet people with Alzheimer's disease and their families.

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