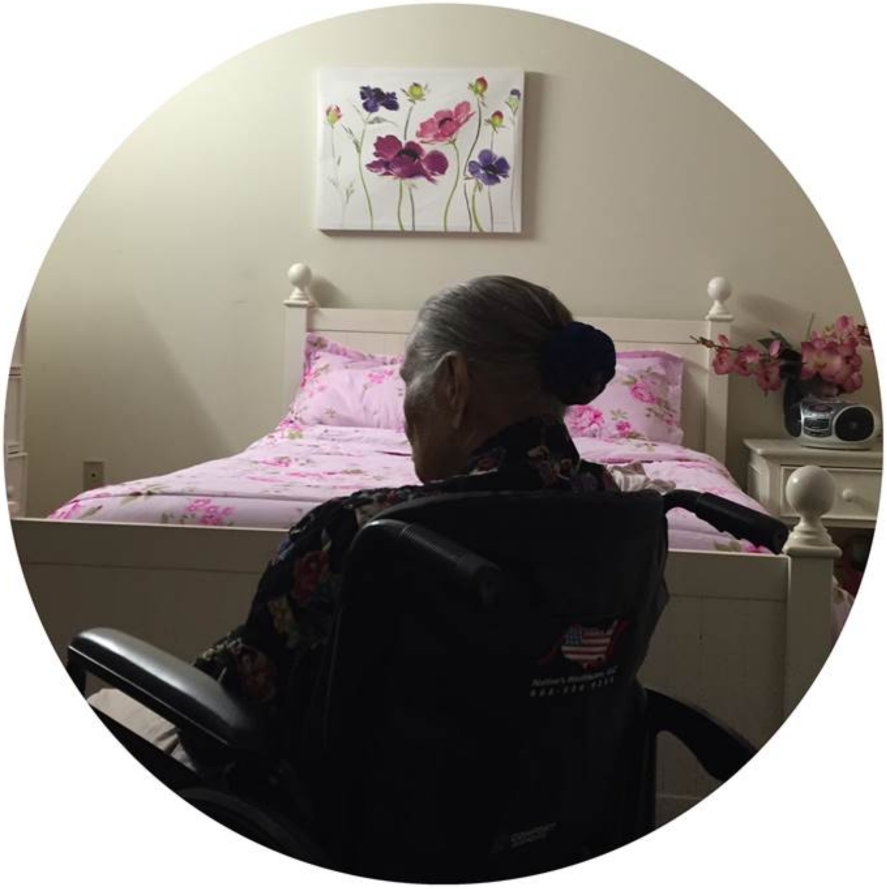
REFLECTIONS

NARRATIVES of PROFESSIONAL HELPING



Special Issue
Relative Caregiving
Priscilla A. Gibson and Sandra Edmonds Crewe
Guest Editors

Volume 20, Number 3 Summer 2014

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PUBLISHED BY CLEVELAND STATE UNIVERSITY SCHOOL OF SOCIAL WORK

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Current Issue Cover: Thelma Jennings Edmonds, Age 90, Resident of Assisted Housing. Photograph by her daughter Sandra Edmonds Crewe, used with family permission. Cropping by Robin Richesson.

ISSN - 1080-0220. Published using the Public Knowledge Project's open source Open Journal Systems software. Hosted at Gossamer Threads. Indexed in Social Work Abstracts and Social Services Abstracts. Full text available in EBSCOhost SocIndex and Proquest Research Library. Please see website at www.rnoph.org for information on supporting the journal as an individual or institutional Friend of Reflections. This issue was published in December 2015. The backdated volume and issue numbers are as noted on the cover and in the table of contents.   This standard journal practice will continue until the journal is up to date with its publishing schedule, which will be achieved in 2016.

Introduction to the Special Issue on Relative Caregiving

Priscilla A. Gibson & Sandra Edmonds Crewe, Guest Editors

Abstract: This letter serves to introduce the special issue on Relative Caregiving. This issue includes personal narratives on caregiving experiences.

Keywords: relative caregiving, special issues, special themed sessions

Relative caregiving is very special to both of us because we are personally connected through our research agendas and experiences as caregivers to various family members, respectively. We realized that caregiving inherently carries emotional, cognitive and physical aspects that bode well with narratives especially because of its accompanying complexities. Whether caring for parents, spouses, siblings, relatives who are children, or other relatives, caregivers have a myriad of feelings about all aspects of their experiences that come with changes in physical tasks as well as negotiating emotional and physical spaces. Often these complexities are not seen as we in society assume responsibilities for relative caregiving that have been passed on from generation-to-generation.

Governmental systems also view relative caregiving as a duty falling within the family's sphere of responsibility. Thus, caregiving is an area where there is consensus about the central role of the family. While there is the recognition of the importance of governmental support as it relates to access and affordability, the family is the focal point. Because of this, we concur that narratives delving into the personal lives of authors would provide a valuable resource in our endless search for new ways to enhance quality of life throughout the life span.

Although all families seem to share in the responsibility of caring for relatives or kin, some ethnic and racial groups have a more pronounced historical role in that they were denied equal access to resources needed to care for relatives. In the absence of a strong governmental system to support the needs of historically oppressed groups, the family became the social welfare safety net (Crewe & Cole, 2015). While this is considered a cultural strength (Gibson, 2014), socio-economic disparities often created a heavier demand for relatives to step up to ensure the well-being of their vulnerable relative regardless of the impact on the family. For example, grandparent caregivers have been assuming the role as primary caregivers for their grandchildren, in order to prevent placement with strangers in the public child welfare foster care system. Doing so is a duty to keep the family together; yet caring for relatives often places fragile families in a more vulnerable situation including neglecting their own health and well-being. Like caregivers for grandchildren, adult children have been making enormous sacrifices, such as moving their vulnerable parents or other family members into their household or being forced to make regular visits to a care facility to ensure that they receive proper and timely care. From this vantage point, relative caregiving can be conceptualized as an intervention to protect and defer harm to love one.

Given this information, experiences of relative caregiving contain rich narratives about thoughts, feelings, surprises and interactions with others, including social systems. For example, interactions between and among family members who have varying levels of agreement about the caregiving arrangement and treatment of the care receiver. I (Priscilla) remember that with my mother who had dementia and was in a care facility. My sisters (one older and the other, younger) and my brother and I really bonded in our efforts to obtain quality care for her. Each assumed a different role and carried it out while also apprising others of the tasks. Yet, we differed in terms of the best way to communicate with the facility staff. Having lived continuously in our small town, my oldest sister thought it was best to talk with each staff person individually.

My youngest sister and I, having moved away as young adults and living in metropolitan areas, went straight to the administrator or nursing supervisor with our complaints. We often joked among ourselves that the staff, who included many peers from our childhood – and who were steeped in the small rural community's tradition of labeling people by their behavior – had special names for us. For my youngest sister who lives in Maryland, she may have been labeled the "Wicked Witch of the East" and for me who lives in Minnesota, the "Wicked Witch of the West". My brother continued in his family role as logical negotiator, loving son and dutiful sibling to very bossy sisters.

As I (Priscilla) collected data during my research with grandmothers as relative caregivers, I was privileged to hear very personal interactions among family members, some of whom not only questioned the caregiving of a grandchild but opposed it because of the many lifestyle changes that the grandmother was forced to endure. I was deeply touched and wondered about the changes made by my great-grandmother who was the caregiver for my mother and some of her cousins. I am fully supportive of relative caregiving yet know that it is not without emotional and physical labor. It is indeed work.

When social systems at the macro level are involved, that adds another level of complexity. Indeed, in this instance, caregiving of an older parent or relative has been labeled as a contested space, meaning viewing the home as a therapeutic space that is then changed when professionals enter with their many recommendations, some of which demands involuntary changes from the caregiver (Dyck, Kontos, Angus & Mckeever, 2005). I think that caregiving for grandchildren under the rules and regulations of child protective services in formal or public kinship care or kinship foster care is congruent with the contested space conceptualization.

The philosophy of caregiving starts at an early age. As children we observe how our circle of relatives and friends are cared for and about. Often the care of grandparent(s) is the introductory lesson on caregiving. As a child I (Sandra) learned early the various roles assumed in caring for older persons in the family. I understood that there were “live-in” caregivers who assumed primary roles and “live-out” caregivers who assumed different, yet valued, responsibilities. The gender roles clearly emerged as well as the sibling views (often differing) about quality of care. I also observed classmates and relatives who were under the care of their grandparents. From my child's worldview, caregiving was a part of life. During my formative years, I observed family members at their best and their worst as the added demands of caregiving entered their worlds. Where there was sibling camaraderie, it exuded in beautiful ways. Each member assumed various caregiving tasks aligned with their work schedule, skill sets, or family dynamics. For these families, caring for relatives was organic with benefits to all involved in the exchange. Where there was family rivalry or disconnectedness, it spilled over into the caregiving responsibilities and often strained family relationships. In these situations, family members were at odds with each other often because one or more persons seemed to be “missing in action” in the care plan and other family members were not giving them a pass. Yet others, I observed, assumed the caregiving role with little room for others to help. They took on the caregiving with an iron hand or you might say that they were ‘helicopter’ caregivers.

Another of my early observations of relative caregiving centered on the personality of the person receiving care. Not only were the caregivers given “pet names” that mirrored their approaches to caregiving (by the way my [Sandra] pet name is ‘the General’), the care receiver was also characterized by how they responded to the caregiver or the circle of support. I recall a friend stating that her “Mom was a joy to care for” as compared with her Dad whom she described as “hell on wheels.” The caregiver-care receiver dyad is powerfully presented by the authors through their narratives.

As a caregiver for my 90 year old mother with Alzheimer’s Disease, I (Sandra) am often asked if she still knows me. I reply that she knows me 10% of the time and I know her 100% of the time, thus we have a 110% connection. Whether she knows me or not, sometimes she simply says the right thing. For example, when I comb her hair, she laments about how good it feels and how much she loves me for combing her hair. On these days the 10% is a home run experience! Hopefully, our narratives, add to the appreciation of the complexity of the relative caregiving experience and acknowledge in their unique ways that it is reciprocal – providing irrevocable benefits to both relative caregiver and care receiver.

Professionals like social workers are uniquely prepared to understand and carry out the responsibilities of caregiving for relatives. Our professional skills and abilities enable us to have more effective dialogue with the health care network as well as other support systems. We share a common language related to assessment, diagnosis, planning and advocacy, etc. Just this week, I was able to intervene to receive an expedited utilization review for my sister from an insurance company. I understood the process and was considered a peer. Yet, there is another side to consider. As professionals, we as well as others hold ourselves to higher standards and experience – producing what I term as 'professional embarrassment' – when we miss warning signals, fail to act on what we know, or simply do not know what is coming. As I reflect upon my caregiving journey with my mother who has Alzheimer's disease, I am often told how lucky she is to have a social worker/gerontologist as a daughter.

While this is true, the dual relationship sometimes comes at a cost because of assumptions that I need less support than others or have the self-awareness to ask for support. This is compounded by my own guilt when I fail to recognize a problem and jump in with my "superwoman social work powers." The narratives in this issue speak very passionately about the benefit/burden experienced as the authors care for their relatives. While most express the tremendous value that being a social worker affords related to the understanding of the needs of their loved ones – identifying resources, and strategies to access them – they also open their private spaces and let us see their more vulnerable side, such as their concerns about their inability to get it totally right for their own family members, despite their resourcefulness as social workers. These reflections from social workers will be of benefit to social work students, social work educators and social work practitioners.

In this special issue of relative caregiving, we the editors were pleased to include five excellent and rich narratives. Using a social work lens, Mulvaney shares her personal experiences as the caregiver of her father who has been diagnosed with Alzheimer's disease. She illustrates how this disease has been pervasive in her life and its effect on her relationship with her father. Reilly-Sandoval narrates how her family's culture had an influence on the caregiving of her mother and relationships with other family members. Her story informs us about commonalities and differences in family relationships and support systems. Whitaker's story illustrates her experiences using her professional social work skills in the care of her mother. Her story reveals that professional training does not deter strong personal feelings during observations of a family member's struggles. Eastman's story digs deep into the psyche of professional human service workers with her sharing of content that resulted in embarrassment about missing signs of dementia. She bravely shares feelings that are not always present in our professional persona. Jones describes her life as a caregiver to her mother, providing meaningful insights into the strong role of culture in relative caregiving. Her experiences despite being a distance caregiver reminds us of the emotional labor of caregiving and the importance of self-care while playing the role.

Some final very personal questions may be on the minds and in the hearts of the majority of people, especially at certain ages: "Who will be my caregiver? Will I get good care? And how much control will I have?" If one lives long enough, regardless of profession, resources and family members, caregiving may be needed. In addition, we might ask: "Who and under what circumstances might I be called upon to become a caregiver? Will it be for a young relative or an older one?" Our affectional ties are such that it could happen to anyone of us.

Working with the contents of this issue has forced us to reflect on how caregiving touches all of our lives. While most of us expect to become engaged in some aspect of caregiving, rarely are we prepared when the knock comes to our door. These reflections provide a valuable context that we hope will assist you as you engage in self-care or work with others who are caregivers. As you read the narratives, like us, you will shed a tear, laugh as you recall similar situations, and wonder how the authors knew so much about your experiences. We hope that you will also grasp the value of narratives in ensuring that our work as caregivers is better understood, supported and resourced. Most importantly, we hope that the openness and heartfelt exchange of experiences will be a balm for some and an anchor in the storm for others.

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

Elizabeth Mulvaney

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.

Keywords: professional helping, caregiving, gerontology, dementia

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 (Brodaty & 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 (Brodaty & Donkin, 2009). Additionally, as the care takes on a bigger and bigger role, the caregiver loses contact with his/her social connections (Brodaty & 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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Full Circle: A Daughter's Perspective

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Abstract: This narrative is a story about the author's experience with maternal caregiving and discusses situations involving aging and chronic illness. The author describes how culture impacts caregiving, and how the author learned to be respectful of her mother's culture while managing the symptoms of chronic illness. This is also a story of sisterhood, of relationships lost and then rebuilt through the practice of relative caregiving. Finally, this is a story of hope amid unhappy circumstances of a cancer diagnosis, and how caregiving of a parent leads an adult child full circle; from being cared for, to caring for, and then to be cared for again by family.

Keywords: maternal caregiving, sisterhood, cancer, relationships, aging

As the youngest of four girls, the prospect of becoming a caregiver to my parents never crossed my mind. My family is multiracial. My mother was born and reared in Japan, married my father at 17 years old, and moved to the U.S. during the Korean War. My father hailed from Chicago, Illinois, and while his ethnic background was diverse, it was the Irish and German bloodlines that were mostly promoted in his identity. While I attended local public schools or Department of Defense schools when we lived in Germany, I absorbed traditional "American" values and beliefs. However, the influence of my mother's culture was much more subtle. My mother quietly ingrained some Japanese values and beliefs in the way she kept house, served meals, and communicated with us. Therefore, I "knew" I would never be called on to provide caregiving for my parents. First, my brother was responsible for my parents. Although he was a year younger than me, he was the oldest (and only) male child in the family. It was his shoulders that were responsible for the financial and physical well-being of my parents. If he was not physically present to take care of my parents, then my oldest sister would. The caregiving responsibilities would fall to each successive sister, and I was the youngest. There were astronomical odds of all of my siblings being unable to care for my parents. Despite the odds against me, I became a caretaker of my mother in her later years.

My father passed away when my mother was 48 years old. My three older sisters had emancipated from home by that time and were raising families of their own. I left home a few years later, got married, and began raising my own family halfway across the country. The marriage was rocky from the start, and after four years, I returned to Colorado and divorced. My mother welcomed me and my two children with open arms, providing much needed housing, financial and emotional support. I was able to return to school and earn my Bachelor's degree. By then, my mother was almost 60 years old, and it was apparent that my children needed more consistent child care arrangements. We agreed that she would retire and be a full-time caretaker for my children.

I did not mean to stay with her for more than a few years after I returned to Colorado, but we discovered that living together was mutually beneficial. It certainly was not easy, especially in the beginning. We had to realign our relationship. She had to learn to view me as an adult, and to respect my parental authority with my children. I had to learn to not regress into a child and expect my mother to do everything for me. By the time I finished my Bachelor's degree, we had ironed out most of the wrinkles in our relationship. After a few years, I returned to school to earn my Master's in Social Work, while working full-time at a youth and family agency. My mother stepped into the role of primary caretaker for all of us. I doubt that I would have been able to finish my degree in a timely manner while working full-time and rearing two children as a single parent if she had not been there to help me.

We ended up living together for almost 20 years. Slowly, during that time, my mother became unable to do her usual tasks. Walking up and down the stairs became more difficult for her, and she began to develop gout and high blood pressure. Her eyesight began to fail. Driving with her was slightly terrifying. By then, my children were in high school and between the three of us we were able to drive her to wherever she needed to go. When she tried to renew her driver's license, she failed the eye test. I think all of us were relieved to know that she would not be driving anymore, including my mom. As a social worker, I was concerned that she might feel trapped without transportation, and so my children and I tried to ensure that we were available whenever she wanted to go somewhere. However, she was concerned about being a "burden" on us, and would often use public transportation instead of having us drive her somewhere. No matter how often we told her that we enjoyed driving her around, or that it was not a bother at all, she still insisted on using public transportation for most errands.

Her oppositional strain ran through most of my attempts to help her. I attended doctor appointments with her and learned what she needed to do to control her high blood pressure and gout. I bought her a food scale to measure her protein intake, and a walker to help her remain mobile during the worst of her gout attacks. She steadfastly refused to change her diet, stating, "That's what I have pills for." During the gout attacks, when I was applying compresses, she would swear she was changing her diet, but once the attack was over, she would continue to eat as she wished. No amount of bribing, cajoling, and reminding could get her to change her diet at all. My frustration with her oppositional behavior led me to reflect on her reasons for insisting on doing everything her own way. While I had never been to Japan, nor studied the culture, I had absorbed enough from my mother to realize that her cultural beliefs led her to be reluctant to inconvenience anyone. This, combined with her strong sense of independence led to her refusal to change her lifestyle and accept help from us. I finally realized that I did not need to manage my mother, I needed to support her through the gout attacks and any other illnesses. I also learned to rejoice at small victories, such as when I convinced her to use low sodium soy sauce instead of the regular stuff.

My brother was living almost 900 miles away, as he was active duty military. Two of my sisters were estranged from the family and not living in the same town. My other sister lived just a few miles away, and would provide transportation to my mother if needed. However, this sister was not in good health herself, so we rarely asked her for help. Sadly, this sister died a few years later, and my mother decided that she wanted to move into senior housing. I was working in a neighboring town by then, and commuting on a daily basis. My children were emancipating, and my mother felt this was a good time for both of us to move. So we went our separate ways, with almost 40 miles separating us. She was happy in her new place, and enjoyed going to a neighboring park, or taking all day to do shopping. I visited her weekly, and ran errands with her if she wanted. Things appeared to be going well for her, except for a cough that she just could not seem to shake. She stated she must be allergic to something, and I kept asking her to talk to her doctor. As usual, my mother insisted this was much ado about nothing, but promised to ask about it at her next regularly scheduled doctor's visit.

At her next doctor's visit, they took an x-ray of her chest. The diagnosis was small cell carcinoma, lung cancer. Her case was so advanced, they immediately scheduled her for treatment. The next few days were a blur. As strange as it may seem, I never imagined my life without my mother. My vision of the future included us taking trips together, enjoying some quiet time without the hustle and bustle of young children or the hectic schedule of a social work career.

I felt completely alone, without a confidante, as my two remaining sisters were estranged and my brother was more concerned with the specifics of my mother's treatment than processing our feelings about the event. I had a lovely support system of friends and co-workers, but I dearly missed my sisters. As children, we had all been very close. There were only 7 years separating the oldest and youngest child, so we played together and confided in each other. While growing up, I shared a room with my sister who was closest to me in age. She was only two years older than me, and we stayed up many nights, talking about our hopes and dreams for the future and gossiping about the other students in our school. By this time, we were living in the same town, only a few miles from each other, but I was afraid to make contact as our last interaction was not pleasant. This is what lead to her estrangement from the family.

My mother had contacted my sister shortly after she moved into senior housing, and the two of them had begun to rebuild their relationship. It was a few days after the cancer diagnosis, that my sister asked my mother to have me meet her at my mother's place. When I arrived, she immediately came forward and hugged me. I was overwhelmed with emotion. I finally had my sister back. We cried together and tried to catch up on the years that we missed, then we began to discuss my mother's diagnosis and how we could partner to help her. As usual, my mother was adamant that we were not to inconvenience ourselves on her behalf. But this time, I had an ally, and my sister and I were able to convince her to allow us to help.

Because of our work schedules, my sister took the bulk of appointments for chemotherapy and radiation. She organized all of the medical information into a binder that we were able to take with us to each appointment. Although she was not a social worker, my sister even created record of contact notes for us. When she was unable to make an appointment or pick up medication, she called me and I was able to do the task. We both spent many hours with my mother in her home, visiting with her and doing what we could to help her feel comfortable. We were able to laugh together, cry, and reminisce about our childhood. We were pleased to notice how alike we were in thought and deed, even though we had spent many years apart. Even though my mother's medical situation was serious, I felt a sense of comfort in having my "big sister" by my side.

Our story is not over yet. My mother successfully completed her treatment and the cancer was in remission. Unfortunately, it returned a few months later, and she is now enrolled in hospice services. My mother's tenacity has made all the difference, however. It has been over a year since her recurrence. Although she was expected to live just months, she is still in very good physical condition. She walks daily, still does her own grocery shopping most weeks, and enjoys the frequent visits by family. I have been fortunate to begin spending holidays with my sister and her family and to reconnect with them. While most people would view a cancer diagnosis as a catastrophic life event leading to death, it has actually provided an avenue for reconnection, growth and resolution for my family. I am grateful for every day that I have with my mother, allowing me to verbalize and to show her how much I care. And I am grateful for the connection I have built with my sister and her family. I have come full circle, from being taken care of by my mother, to being one of her caretakers, but I do not have to face this task alone.

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Letting Go and Learning to Float: A Caregiver's Story

Tracy R. Whitaker

Abstract: Professional training prepares one for many things, but not necessarily for becoming a caregiver. Although I was trained as a social worker, it was a geriatric care manager who provided the resources and hope that allowed me to adjust to the changes in my life after my mother had a stroke. This narrative discusses some of resistance that initially hindered my professional help-seeking as well as the benefits of finally reaching out for assistance.

Keywords: professional help-seeking; relative caregiving, role conflict, helping, help-seeking

The world changed one day. And, after that day, it seemed as though nothing would ever be the way it was. But this was not the kind of wonderful change, like falling in love or having a baby when the world suddenly seems brighter and better. This was a darker shift. A disaster. Instead of a new piece of the world opening up; it seemed a piece of the world had forever closed. My world changed like this in January 2011.

In one day, the same hand that had sewn an awe-inspiring Easter bunny costume for my school play and then 40 years later had made an equally awesome lion costume for my five-year old, could not move. At all. In one day, a mind that had been renowned for its sharpness, was suddenly struggling to understand a new reality and protesting every new step. In one day, all of my professional social work training seemed to abandon me and I knew nothing except that I needed guidance and help to survive this nightmare.

As our family attempted to adjust to the changes that the stroke had brought, we were also holding steadfast to the vision that they were all temporary, and that eventually, with work, money, and effort, the woman who was our mother would return in full force. Someone I didn't quite recognize had replaced my mother (Boss & Couden, 2002). The mother who was an award-winning children's author; the mother who taught chair yoga in her senior complex; the mother who exercised religiously and paid meticulous attention to her diet; the mom who was ferociously independent; the grandmother who had provided daily nurturing and companionship for my son for the ten years of his life; and, most importantly, (to me), the mom who was my closest friend and confidant. We simply needed to wait for her to return.

After a three-week stint in the hospital initially following the stroke, and a four-month stay in short-term rehab, my mom was discharged. Mom would need 24-hour assistance, as she was no longer able to handle routine activities, like bathing and preparing food alone. We arranged to have a caregiver during the day while I worked, but I decided to take on the evening and overnight care duties. My mother lived just five minutes from my home, and I would be able to easily see my husband and son every day, so I moved in with her to help her adjust to living at home again. I was completely unprepared for the level of caregiving that my mom required and for the multiple impacts on all members of our family (Lutz, Young, Cox, Martz & Creasy, 2011; Ski, Castle, Lautenschlager, Moore & Thompson, 2015). My husband prepared dinner every evening at her home after picking up our son from school. We ate dinner and watched television together and tried to maintain as much normalcy as possible. At my mom's, I slept on the couch in the living room, where my sleep was frequently interrupted by mom's needs during the night.

My brother, husband and I figured that Mom would be back to her former, if slightly altered self, by the time school resumed in August. To make this fantasy come true, I willed myself to see changes and improvements that were perhaps there, but not in the magnitude I declared. I was convinced that she was getting stronger and that if she just tried a bit harder, she would regain her former self-sufficiency. I could not understand why she resisted using the tools we purchased that would help her get dressed, or make going to the restroom easier. Between my denial and her new reality, our relationship teetered on the edge of destruction. I could not accept that she had a brain injury, and that she would often be forgetful or misinterpret what was going on around her (Grant Glandon, Elliot, Giger & Weaver, 2015). These mental lapses I took as personal affronts. At all costs, I was going to save her from going into the abyss of dementia.

> *It is as if she is drowning. I reach for her and pull her back to the surface – hard. Sometimes too hard. I don't mean to be rough or to inflict pain, but she is drowning and I can't let her go. I frantically push the water away from her face, and she struggles to be free. Her eyes fill with tears as I drag her back to the shore and insist that she walk on firm, solid ground. Familiar ground. Like she used to. Before. She is weary and so am I. But for a moment, we are stable. She leans on me for support, but I want her to again embrace the stability that she needs and that I crave. We stand together, physically and emotionally spent. I have succeeded and for a moment, she is not drowning. I don't understand why she is fighting against me. I know that she does not want to go under – that she longs for the clarity and safety of terra firma. So whenever I see her slightly drifting, I grab her attention, so that she doesn't get too far away where I can no longer reach her.*

In my efforts to save her, I was too often short-tempered. I was more often, exhausted. As spring turned to summer, then to fall, then to winter, my family had lost all semblance of our former routine (Lutz et al, 2011). As school resumed, I checked my son's homework intermittently, and tried to keep up with his daily activities. I was becoming concerned about how he was doing as he seemed generally sad. Each day, when I kissed my guys good-bye, I wondered if they were really doing okay on their own. I felt guilty, and obligated. I felt like I was simultaneously in the right place and the wrong place (Pierce, Thompson, Govoni & Steiner, 2012). I was really tired, but mostly tired of avoiding the fact that mom was not coming back, at least not as I had hoped (Saban & Hogan, 2012).

> *I put my hand out to touch her hand and can't find it. I feel the same, familiar terror – I am really going to lose her this time. I am reaching, but I can't see her clearly. I feel the water and realize that she is fine, and it is me who is underwater. I am drowning. And she can't save me. But I want her to save me. I am scared and unready for the challenge of being the one in charge. She has always been there for me, and now the thought of being there for her, without her being there to guide me, literally pulls the breath of me-suddenly and sharply. I am going through the motions, so unsure, so overwhelmed and so scared of making the wrong choice, or a bad decision. I have always leaned on her, probably too much and for too long. I want to tell her – no, I need to tell her – that I am losing my best friend and it makes me cry inside a little every day.*

I literally gave out. I had very little left to give, but the relationship I had so treasured was becoming more fractured every day. There were good days, of course, with laughter and conversation. But there were more days that were marked by frustration and sadness. It seemed as if my earnest attempts to love and to be a good daughter, were sometimes being rebuffed and I just could not make things right. I wanted desperately to be a good caregiver, but felt I was falling short (Saban & Hogan, 2012). I was going to hell on the path paved with my good intentions, and taking my loved ones with me.

It was at a point of pure desperation when I finally called a geriatric care management service. I was sure that geriatric care management was a high-priced term for things I already knew how to do. But I was also becoming increasingly sure that I did not know enough. I kept waiting for my professional skills to kick in. As a social worker, I knew how to be positive, supportive and strengths-based. But I felt like I was drawing from an empty well. I am not sure why I was resistant to acknowledging another social worker's expertise and experience. Perhaps it was because I was afraid of being judged, not only for my lack of knowledge, but also, maybe, for not doing such a good job with my mom. In addition, I could not initially justify hiring someone with the same skills and training that I possessed. We were spending lots of money – on physical therapy, medical supplies and aids, and caregivers, but we were not seeing a great return on these investments. I certainly didn't want to "throw money away" on someone who was my professional peer. Despite my training and years of experience, it was becoming increasingly clear, however, that I did not possess the objectivity to engage my professional use of self. I flitted constantly and uncomfortably between my roles as child, parent, caregiver, and advocate. For sure, I did not seem to know enough to keep my mother both comfortable and happy on a predictable basis. So, I put professional training and pride aside, and once again, my world changed.

The geriatric care manager entered our world just as a social worker should. She met my family where we were, in that moment, with all of our strengths and challenges (Wideman, 2012). She observed the artifacts that had shaped my mother's life prior to the stroke. She saw my mother's artwork and her children's book. She saw the bookshelf full of eclectic titles and topics. She saw that things had changed significantly for my family, and she helped us acknowledge those losses. In my mind, the stroke had left my mom in pieces. What had been a beautiful fabric was now mostly remnants and all I could see was the "hole" that was left.

The geriatric care manager, however, was able to see the "whole" that was still there (Boss, 2010). She helped our family to see that some things were the same. There was still my mom's quick wit and our gentle teasing and laughter. There was still hope. There was still love. Her lack of comparison to what was, helped us all embrace what is. Where I could see only someone who could no longer swim; she could see someone who was now more comfortable floating. She could also see someone whose very adulthood had been diminished by needing assistance with previously private activities, and she validated my mother's concerns and wishes in ways that I had not and could not. She could hear my mother in her current voice, not as a mere echo of her former self. She helped my family regain its collective power. She restored our sense of options and choices, as well as our hope that together we could make a plan that would meet our needs, individually and as a family (Kane, 2011). She helped me relinquish some of the roles that did not fit, and embrace the one true role that still did – daughter.

This experience has helped me identify and understand important implications for social work practice with caregivers. These implications include, the acknowledgment of grief and loss related to sudden and traumatic illness, strategies for coping, particularly with immediate family members and the importance of recognizing the limitations of professional training in personal crises. It is also important that social workers investigate the experiences of caregivers through qualitative research.

> *For a while, I was able to think about how it used to be – when my mom kept me from drowning in self-doubt, or bad relationships, or questionable self-esteem. Her hands reassured me and had supported me with clarity and strength. I never knew her to be afraid, just strong and sure. But now, she was scared, and needed me to be a safe haven. I realized that she wasn't drowning and didn't want to be rescued. I had been the one screaming for help. With the help of our lifeguard, I began to let go of the struggle and trust the waves that had changed the landscape of our lives. I close my eyes and gently, gently, brush her hair and rub her shoulders. I tell her that she is loved and that she is safe. I return the gift of reassurance. I am letting go and learning to float – prepared to go where the water will take us – together.*

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Lessons Learned: Experiences of a Caregiver

Brenda Joy Eastman

Abstract: In the following narrative, the author shares experiences from the time when she was the full time caregiver for her mother who suffered from dementia. She reflects on the lasting impact this experience had on her life and her identity as a social work practitioner and educator.

Keywords: dementia, adult, eldercare, caregiving, care provider, social work

Introduction

When I read the call for papers for reflections on caregiving, I felt that I had a story to share. The time I spent being the primary caregiver for my mother was one that I have never regretted, but it was also a humbling time filled with mixed emotions, doubts, and frustration. I experienced moments of contentment as well as exasperation. There were many lessons that I learned: 1) one can never be objective about or prepared for the experience; 2) caring for a loved one with dementia means navigating a “maze” of policies and services that is illogical and confusing at best; and, 3) solace can come from the most unexpected places.

My mother was the most independent woman I have ever known and in my eyes, she was infallible. She had endured many experiences and environments that would have broken the spirit of most people: an abusive marriage; a nomadic existence in a military culture which isolated her from extended family; serving as a safety zone for her children from the nightmare behaviors of a substance abusing parent; and then, the sudden, violent loss of a spouse who though abusive was still the only long term relationship she had known. During her later adulthood, she suffered from chronic health issues that included hyperparathyroidism (collateral damage from the removal of her diseased thyroid); chronic kidney disease; Non-Hodgkin’s Lymphoma, and a bowel obstruction that necessitated the performance of a colostomy with no option for reversal. Throughout these years, I was able to care for my mother and our bond grew stronger as is often the case with mothers and daughters.

The adage “hindsight is always 20-20" comes to mind when I think back to the process of recognizing and acknowledging my mother’s dementia. I can now see the progression of behaviors that were clear “markers” of the disease’s early progression. It is embarrassing to admit, but as many people do, I dismissed most of them for years. It was not until the time of her recovery from her colostomy that I was willing to approach the possibility that my mother had dementia. This alone was a huge learning experience because there are numerous variations of the disease and the diagnosis is maddening unless it falls under the umbrella of a type that can be “visibly observed”. Shortly after my mother’s ostomy, she began to share with me the content of her “visions”, how she was joyful that her mother (long deceased) was with her and that she would find herself in a garden with her mother and sisters (also deceased). She also experienced frightening hallucinations so devastating that she would need to be held and comforted for hours until the feelings of despair and hopelessness subsided. After numerous doctor appointments with her primary care providers and specialists, a MRI was taken, past scans and MRI’s were collected, and a diagnosis rendered: multi-infarct vascular dementia. Her disease would continue to progress and her abilities to manage her life independently would disappear. This was all uncharted territory for me and that surprised me. I thought that as a professional social worker I would be able to handle this in a professional and objective manner. I couldn’t have been more wrong. When you are caring for a parent suffering from the devastating disease of dementia, when you are watching that person lose herself to the disease, you become immersed in an emotional vortex. My mother had dementia, and my life changed forever.

The Transition to Full Time Caregiving

In what I now call a futile effort to prepare myself, I first contacted my cousins and asked them to recount their experiences and describe their strategies of coping while caring for sick family members. I read everything I thought would provide me with a “plan of action” for becoming the caregiver for a parent with dementia. This included popular books such as *The 36 Hour Day* by Mace & Robbins (2009) and web sites such as Seniorcare.com. I conducted literature searches using social work and gerontology data bases. I would like to inject my biased opinion here, one that surprises me to say: speaking with relatives and friends who have been caregivers is far more informative than any of the material I read that was authored from either a clinician's or an academic researcher's perspective. I was scared when I realized that my armor as a professional social worker would not immunize me from the sadness, anger, guilt, and isolation that were coming my way. My fears during the transition from an academic and clinician to a caregiver lessened when I started "letting go" of my "professional self" and started connecting directly with persons I knew had been down this path before me. This is one of the most surprising lessons I learned and I am glad to pass it on.

The best perspective I can offer about transitioning to caregiver is that no two transitions are alike; the experience is singular, and there are absolutely NO rules. Step away from what you feel you should know and embrace what makes sense for your reality. My initial months at my mother's home were filled with a whirlwind of emotions that had to take a back seat to my mother's needs. My first priority had to be to learn how to care for my mother. I remember coming across a number of discussion forums on various web sites (i.e. AARP, Caregivers.com, etc.) and one discussion in particular caught my attention. It was titled, "What do you wish you knew when you first started caregiving that you know now"? I found kinship in reading the pages of individual contributions and narratives that were posted. It was something I could go to anytime of the day or night and yes, I could share my thoughts and feelings. It is often said that knowing you are not alone is comforting and I found that homespun wisdom to be true. The simple sharing of emotions and experiences even though it was anonymous and with strangers nevertheless gave me more comfort and reassurance than any other source both during my initial transition as well as throughout the time I shared with Mom.

The Maze

As a social worker, I am not surprised by the complications surrounding our health care system, social security system, and the various governmental branches that must be navigated while seeking services for a child, an adult or an elder. I knew about guardianships and conservatorships and I successfully navigated the state court to obtain them for my mother. I was glad that I had worked in a social work position that interfaced with the criminal justice courts because going to court on behalf of my mother did not intimidate me although I realize it may be intimidating to others who have never had contact with our legal system. Believe it or not, the court system was the simplest and clearest to navigate, especially compared with what came next: dealing with my mother's residency status. My mother was not a naturalized U.S. citizen; she was a legal alien resident who had always had a green card since her marriage to my father in 1950. She maintained her Canadian citizenship. As I was going through her mail, a letter arrived from the United States Citizenship and Immigration Services notifying my mother of a hearing to determine whether or not she could maintain her status as a legal alien. Mom had not renewed her green card the year before I moved in with her. After searching through the house, I found the renewal notice in the dining room china cabinet. I was on the phone, confident that I could resolve the issue quickly. I believe I spent at least ten hours on hold and 45 minutes actually speaking with someone. Despite my efforts, I had to travel over 100 miles for a hearing with my mother. After presenting court orders related to my status, her medical documentation, and an explanation of why the card was not renewed, we left with a temporary card and went through a series of home visits that I can only assume were aimed at verifying that my mother had dementia and that I did indeed reside full time as her caregiver.

I had now earned a new badge of distinction: I was a maze runner. I have advantages that others thrown into care giving probably don't have. My education and profession enabled me to navigate both the court system in Virginia and deal with the U.S. Department of Citizenship and Immigration. My father's military career afforded my mother excellent medical coverage and pension benefits. As an online teacher, I was comfortable using the Internet and visiting discussion boards. By comparing my experience to that of others, I found out just how fortunate I was: I had a working knowledge of government agencies; I did not have the pressure of huge medical bills; and I had a job teaching online courses that enabled me to be in Virginia caring for my mother while I was teaching "at" a North Carolina university.

Solace

As my mother's disease progressed, so did my feelings of isolation, anger, and guilt. I found myself logging onto my computer frequently to check on the latest postings on the caregiver discussion boards I was following. The majority of my virtual community members often posted about how isolated they felt from friends, work colleagues, and social networks and I echoed those sentiments. I am not married nor do I have children, but I was filled with compassion and empathy for the persons who posted about wishing their family was more supportive or would offer them a respite to recharge. I was fortunate that my brother and his wife who lived nearby were able to provide me with times of respite. My extended family frequently called, and while they are scattered all across New England and Canada and could not be there in person to help, they were willing to listen to me vent and process my own feelings, they sent me notes of encouragement, and praised me for my efforts. However, I felt too guilty to share this with my virtual community. I had this irrational fear that if I spoke of my support system and my advantages in work and education that I would no longer be accepted by the online community. Reflecting back to these feelings, I now can recognize clearly that these were generated by my growing depression from caregiving. While many of us posted about the importance of keeping in contact with friends and taking time for ourselves, few actually posted about times when they were able to do this. It seemed that we knew what to do but were frozen in immobility and unable to achieve it. I especially remember one post where the author described how her mother's depression had become her depression and how she felt like a prisoner in her own home. This resonated with me because I was now into two years of not living in my own home other than for a quick trip home to pick up mail or take care of work related business that could not be done via internet. A night or weekend in my own home was a vacation, but the elation quickly dissolved when I returned to my mother's home. While I recognize now that I had lows and highs, it is hard to keep that perspective when you are immersed in the experience.

Hard Won Lessons

As a social worker and educator, I now feel more at ease with permitting the client or student to arrive at an "answer" on their own. I feel less pushed as an educator to dissect practice into steps or place behaviors/experiences into categories. I have sometimes frustrated my students in field by not providing definitive answers. I feel this experience of care giving has enabled me to feel comfortable serving as a resource for both my clients and my students by urging and guiding them to explore avenues in order to discover their own style. To this day my personal experience has been translated to one of my favorite policy lectures on being a policy practitioner and the importance of knowing the "system" inside and out that your clients are involved with. In addition, I now make it a point to seek out opportunities to network with other caregivers in order to offer any assistance I can with questions concerning navigation through social policies and services. I wrote this paper to reach others who may be looking for solace to ensure them that they will survive the experience and that this life experience will help them make strides in their own life's journey. The only experience truly wasted is one from which we learn nothing.

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Relative Caregiving: Paying It Forward

Jenny Jones

Abstract: The roles have reversed. Once a child recipient of maternal rearing, I am now a successful adult who dutifully assumes the caregiver role for my mother as she ages. In retrospect, this situation parallels the current statistic: "one in five households in the United States provides support to an aging or disabled family member" (Centers for Disease Control and Prevention, 2015). This article focuses on my personal journey into caregiving and describes my experience as a caregiver for my mother, why I choose to provide care, and the rewards and challenges I have experienced along the way.

Keywords: older adults, caregiving, family support, role reversal, aging, dementia, social work

My Personal Journey

For the past five years I have served as a caregiver to my 84 year old mother. My journey began as a distance caregiver in 2006. According to one study (Collins, Holt, Moore, & Bledsoe, 2003, p. 310), "Distance caregiving practices include frequent contact with parents, mostly by phone; the establishment of arrangements with neighbors or close relatives; and keeping up to date with health-related matters so they could be informed when there were emergencies." At the beginning of this journey, my mother was semi-independent and lived alone in her own home that was located in a small town in the South, approximately 600 miles away from where I lived. Mom retired from the workforce in 2008, two years after I relocated to an area south of Washington DC. At that time, her health was still relatively good, despite her having lived with chronic conditions such as diabetes and hypertension. She was still driving on a regular basis and maintained self-care. She was enjoying her retirement; she had joined various groups at the local senior citizen center such as knitting and crocheting; she also participated in group day trips with the senior center.

These activities were ways to keep her involved with other retired persons while also serving as a form of socialization. In other words, she lead a relatively active and lively life. During this period, my level of distance caregiving included daily check-ins via telephone to inquire about her general wellbeing. I would ask questions about how she spent her day; did she take her medicines; and what did she eat that day? I would also call after each doctor visit to ensure that the visits had gone well and there were no changes to her medications or health status. It was through the daily check-ins that I stayed abreast of how she functioned. At that time, my level of concern for her emotional and physical well-being was moderately low.

In 2010, I began to worry about mom when I learned she had stopped going to the senior center as much as she used to. She began to complain more about not feeling well, and not feeling like preparing meals for herself. By her own admission, she had begun to eat whatever was available that required little preparation, which sometimes included junk food (i.e., sugary, starchy foods that ran her blood sugar level up). In an effort to impact the lack of meal preparation and increase face to face contact with others, I suggested that she enroll in the Meals on Wheels Program as an alternative to unhealthy junk food or skipping meals altogether. Also, the Meals Program was operated through the local senior program and she was familiar with the staff from the program. These ensured two things for me: 1) she received a balanced meal everyday; and 2) she had daily contact with an outside person. As our daily check-ins continued, one day she stated, "I just don't feel good most of the time anymore" and "my eyes don't feel good." She further stated, "I thought after I had the cataract surgery my eyes would feel better, but now they feel worse and I don't feel like driving much anymore." It was through these conversations that I began to realize that my mother's health was declining, and if things continued, her level of care would likely increase and she would require more supervision; the kind of supervision that could be difficult to achieve from a distance. Over the course of the next two years my mother's health continued to wane even more. She had almost stopped driving. Consequently, she had become even more isolated and less compliant with her care; she would not test her blood sugar levels on a daily basis and sometimes was inconsistent with taking her medications. As my mother's health continued to decline, unrelated concerns about her health surfaced: she had a fall in 2011; from the fall we learned that she had arthritis in her knee, which interfered with her mobility. Later that year the doctor raised concerns regarding her vision and the impact the diabetes had on her eyes over the years. Thus, driving was more challenging than before and night driving was out of the question. During this period, on-going telephone updates from her doctors prompted me to travel to where she lived so that I could be physically present for these appointments. The trips were costly and physically taxing. During those visits, I noticed that she became easily frustrated when she was unable to perform simple tasks and she was becoming increasingly more forgetful. Within a six to eight month period, my mother's health continued to decline rapidly. It became clear to me that my mother was likely going to need assistance with her care to remain safely in her home. The time had come for a discussion with her about her continued self care.

Over the next year my mother expressed many times that she wished I didn't live so far away. That was code for "I want you to move home." Statements such as that made me feel guilty about being so far away, thus I began to ponder several questions: How much longer would she be able to live alone unsupervised? How was this going to be handled? What role would my brother or extended family members play in this decision? Would she have to move to the city where I lived, or I was going to have to move closer to her? Truthfully, I was so hoping that the choice would be to move her to the city where I lived.

My mother's rapid change in health status and changes in her behavior had me concerned. Given her inability to care for herself in the way that she had before her health started to decline, and the fact that she had made it clear that she wanted me to move closer to her, I had to make a decision about how best to handle this situation. I began weighing my options and debated whether my best action would be to move my mother to the city where I lived despite the fact that she did not want to move away from her family and the community in which she had lived all of her adult life, or to relocate to be closer to her. After much discussion and contemplating the decision, I decided I should relocate to be closer to her. Let me hasten to say, this decision did not come easy for me. There were many unanswered questions including "What about my professional career? What about my personal life? Do I alter my professional and personal life course? Am I supposed to make such huge sacrifices in life? Why me? Why can't my brother take care of her?" In retrospect, I was frightened about the decision I had made, and was feeling overwhelmed and stressed with the idea of increased caregiver responsibilities.

Why I Choose to Relocate: Paying It Forward

My decision to alter my professional and personal life course was not an easy one, but informed by a couple of reasons: 1) the relationship I have had with my mother throughout my life, and 2) the cultural values and traditions that have been a part of my family for many years. As I reflect on my relationship with my mother, I recall that she and I have always been very close; she was my role model and my source of strength. She is a very proud southern woman with a strong sense of self. Prior to her health declining she had always been independent and self-sufficient with a strong work ethic. These values, norms and character traits have been present throughout my life. My brother and I were raised in an extended family environment that emphasized family as the nucleus of our existence. The overall message was "family takes care of family"; which included children as the preferred helpers, as well as other relatives who also helped with providing caregiver type assistance. My brother's decision to not become the primary caregiver of my mother is not atypical. Traditional African culture reflect that women have always been the caregiver of children and the elderly; engaged in caregiving activities rooted in collective responsibility, communal belief, and mutual aid that extended to families and the community (Wells-Wilborn & Simpson, 2009). Thus, my brother's lack of direct involvement is characterized in a way that is consistent with traditional African and African American culture.

However, my mother and extended family members have always supported and taken care of family. I witnessed my mother and her sister provide care for my grandfather when he was ill with cancer; my cousin cared for her elderly mother when she was battling cancer and kidney failure. These examples of caregiving are a natural part of my family's way of life….paying it forward. So, my decision to take on the role of caregiving of my mother is deeply rooted in family values, and traditional African culture and traditions. African American caregiving values-extended kinship networks, communal beliefs, collective responsibility, and mutual aid-are rooted in West African traditions (McCray, 1980). Contextually, this scenario is consistent with studies of African American elderly that emphasize their strong extended support systems with their cultural (Anderson & Turner, 2010); (Wells-Wilborn & Simpson, 2009); historical, social, and economic roots (Dilworth-Anderson, Goodwin, &Williams, 2004; Cox & Monk, 1996. Therefore, it was a natural, culturally, inherent decision to assume this role.

While intuitively this felt like the right thing to do; to the contrary "was I prepared for it"? "No, I was not." The caregiver role and responsibility came all too soon for me. I had been living comfortably in an urban inner city community for roughly seven years and worked as a faculty member at a local University. I had established a life for myself that I was quite pleased with. I had my friends, community networks, and my work life. For the first time in many years I felt settled; and I had a great life. To give that up was indeed a huge sacrifice. However, the ability to act in this capacity for my mother gave me feelings of peace, because I was giving back to her in a way that was comparable to that which she had shown to me throughout my lifetime. Therefore, when I voluntarily began assuming the relative caregiver role for her, I began to pay my service debt forward.

The Role of Caregiving: A Review of the Literature

According to the National Family Caregiver Support Program (2015), a caregiver is "anyone who provides assistance to another in need." However, when that assistance is structured in nature with routine maintenance, the definition of care becomes much broader and includes a wide range of rehabilitative, restorative and health maintenance services that assist older people with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and the emotional aspects of coping with illness or disability" (NFCSP). Moreover, as the elderly population continues to grow and life expectancy rates increase, the need for outpatient medical services and care by family members and friends has become critical in meeting the needs of older adults. This occurrence has become commonplace among society (Beckett, 2008). Specifically, the literature on relative caregiving documents that one in five households in the United States provides support to an aging or disabled family member for 18 or more hours per week (Mast & Pantaleo, 2012).

Caring for an aging parent can be an overwhelming experience that severely taxes the coping abilities and well-being of the caregiver (Cox & Monk, 1996). Often times, such care entails a variety of supports and responsibilities, many of which can change in intensity and complexity over time. For example, caregiving can start out by simply coordinating services for a loved one (i.e., doctor appointments, meals on wheels, etc.), and over time, progress to entail more time consuming activities such as transportation to and from doctors appointments and managing activities of daily living activities that range from bathing, managing medications, and preparing meals, to heavy lifting, to include transferring the care recipient in and out of bed, helping with physical therapy, injections, feeding tubes or other medical procedures. In small doses, these jobs are manageable. However, having to juggle competing caregiving demands on an ongoing basis, combined with the demands of one's own life can be quite a challenge. Over time, these demands can impact the quality of life for the caregiver. To that end, cultural differences unique to elders and their families shape their views on what aging, health, and end of life mean; and thus, affect expectations about who provides care and what that care will entail (Izal, Montorio, Márquez, & Losada, 2005). My personal journey, as described above provides a snapshot of the transitions/variations and range of experiences one encounters when making the decision to take on being a relative caregiver.

In retrospect, my personal journey into caregiving is consistent with the literature, as the needs of my aging mother are overwhelming at times. Challenges related to balancing a demanding career and personal responsibilities, as well as finding personal time to relax and care for myself while attempting to manage the emotional and physical burdens of caregiving can take its toll, both physically and mentally. At times I have felt totally overwhelmed, stressed, emotionally fatigued, and isolated as I navigate my way through this process, particularly when I attempted to manage my mother's care from a distance.

Benefits/Rewards of Caregiving

When I considered relocating to be closer to my mother and take on a more active role in her care, I thought about the various benefits and rewards associated with this choice. Through our increased interactions, my mother has taught me lessons of sensitivity and caring during our socialization process and in the building of our new relationship; caregiver and care recipient (Piercy & Chapman, 2001). One of the benefits/rewards has been the time we have spent together, as care is given and received. Many old issues between the two of us have been discussed and resolved. New connections have made me think differently about this stage of her life and what this must feel like for her and to acknowledge and respect old roles when she was the caregiver, while addressing the changes in our respective roles. Also, living closer to mother has provided me the opportunity to become closer with extended family members who assist me with her care. On numerous occasions when I have had a conflict in my schedule and I am unable to accompany my mother to medical appointments my cousins will assist with transportation. In addition, they will take on grocery shopping for her and other errands during the week when I am not available. Moreover, my brother avails himself to assist with her care much more than he did prior to my moving closer to her. Hindsight tells me that my brother views caregiving as if it is something a man could or should do. However, I believe the idea of the responsibility of being a primary caregiver was too overwhelming for him to grasp.

Another important aspect of this process that gives me peace is ensuring that her voice and feelings are acknowledged during the decision-making process related to her care, as well as engaging in advocacy efforts to ensure that her needs are met. I remember during one of my mother's doctor visits and the nurse entered at the end of the visit to go over the doctor's instructions; she started speaking directly to me as if my mother wasn't present. My mother turned to the nurse and said, "You can talk to me, not to her; I know what I need to do." I turned my head and just chuckled. That became a teaching moment for me and the nurse; it was clear that my mother wanted to be acknowledged and respected, as well as be an active participant in her the discussions about her care. This was another example of the importance my mother placed on being acknowledged and respected. Despite her declining health, my mother continues to be a very proud woman with a strong sense of self. There are many more examples like this one that makes me smile; continuing to learn from my mother is a welcomed smile.

My earlier work experience as a medical social worker in hospital settings and home health agencies has been a huge benefit to me and my mother as I have moved through this process. I was able to draw on these former experiences when it came to coordinating her care, as well as communicating with doctors, nurses and other health care providers. I was acutely aware that health care settings, like other groups were organizations with their own distinct culture. According to Schein (1992), organizations have cultural norms such as valuing input and teamwork, or professional led decision-making. Organizational cultures often dictate how staff, in this case health care providers treat patients. I was also aware that health settings overtime had indeed changed since I was employed, and the need for me to be present at all time was very important. These experiences, in addition to my social work training have helped me navigate through the health care system.

As I reflect on the early days of this journey it was extremely difficult to get my mother's doctor to speak with me via telephone about her care during routine appointments. Before each visit, I would ask my mother to call me when the doctor entered the examining room; sometimes he would speak to me and other times he would tell her to tell me what he said. Prior to regular involvement with my mother's care planning, I would call the office and leave a message for him to call me back, to no avail. My mother started telling him at each visit that he might as well call me back, because I was not going to stop calling until he talked with me. The calls persisted, and finally one day he called me back, and that was the beginning of developing a relationship with him about my mother's care.

I have worked to hard to develop a relationship with my mother's primary care doctor and the nurses in his office. Needless to say, this has taken time. I had to be focused, organized, and persuasive in my approach. According to Ezell, 2012; Schneider (2001) the tactic of persuasion allows for persistence when it comes to advocacy efforts. As such, persuasion became my primary tactic when it came to asking questions regarding my mother's health care, such as care coordination, medication management, diagnoses, referrals to specialists, and other follow up. Using this approach was rewarding in that it raised awareness by my mother's doctor and his staff of my essential involvement in her care, as well as my role as an outside advocate to monitor her experiences with the health care system at large. Therefore, every contact with a health care provider, I would include in the conversation the concern and care for my mother's health by both my brother and myself.

Given the rapid changes in the healthcare system, many doctors are primarily concerned with the task at hand and do not like to be questioned by non-medical personnel. Oftentimes this does not allow for phone consultations with family members. However, in order to make this process amenable for both my mother's doctor and myself, I employed social work skills specific to engagement, interpersonal communication, and competence to educate the doctors and nurses regarding the importance of communication issues as it relates to my role as my mother's caregiver and advocate. I had to be consistent in my approach, and present at all time. This has made quite the difference in how medical professionals respond to me about her care. The intersectionality of my professional training and my responsibility as a caregiver has been a huge benefit to mother and me. This unique experience of being a professional social worker has positively impacted the level of service delivery to my aging mother.

Challenges I Encountered

The literature suggests that caregiving is never easy regardless of the relationship with a parent or loved one prior to the illness (Rozario, Chadiha, Proctor & Morrow-Howell, 2008). Caregivers are thrust into situations which elicit an array of emotions. These emotions influence how the caregivers will respond. For many caregivers, including professional social workers, private attendants, as well as family members, managing these feelings may be overwhelming and may require professional intervention (Rozario, Chadiha, Proctor & Morrow-Howell, 2008; Parrish & Quinn, 1999). As a caregiver to my mother I have been faced with many of the emotional stressors noted in the literature. At times I have experienced sadness, anger, frustration, isolation, and physical and mental fatigue. Ways in which I have coped and managed those emotions have included relying on the support of friends, family members, colleagues, and other care providers. I have also sought support from health care providers, national and local caregivers associations, the Area Agency on Aging (AAA), National Caregiver Alliance, and the American Association of Retired Persons (AARP).

Caring for my mother has entailed a variety of responsibilities, including her adherence to often complex medication regimes and coordinating medical appointments around my schedule. When I cannot be available, the task of coordinating and arranging transportation with other relatives becomes part of the process. There is the task of food preparation, personal care skills, managing her personal finances, arranging homemaker services, and many others. Balancing these responsibilities has not been easy. The use of community resources such as the local senior program in my mother's home town and private attendants have helped enormously.

Balancing these feelings, along with juggling the demands of my personal and professional work life I am left with little to no time for self-care. This no doubt has been challenging. Some of the steps I have taken to minimize the stress I encounter that comes with the role of caregiving, including a monthly massage, exercise, occasional day spa trips, and mini vacations. While these steps have certainly helped, I continue to struggle with ways to care for myself so that I can remain healthy, both emotionally and physically as I continue to care for my mother and myself.

Implications for Social Work Practice

I am very happy to have had the opportunity to write this article about my personal journey as a relative caregiver to my mother. Writing this article gave me a chance to reflect on my relationship with my mother, as well as my role as a daughter, and a professional social worker. The easiest thing in writing about this experience was I got to tell my story without being hampered. Through this experience I have learned a lot about myself as well as the nature of caregiving.

My personal journey through this process has taken many twists and turns. I have learned many lessons personally and professionally. On a personal level I have learned the importance of patience and compassion when caring for an older adult. I have also learned the importance of asking for help and being open to receiving the help I need from others.

Professionally, I have learned that it is critical for the social work profession to continue to prepare and educate future social workers to provide services to older adult populations, as well as their family members that serve as caregivers. We must integrate information specific to caregiver burnout and coping strategies to assist families in delegating and distributing some of the care responsibilities of providing care to avoid burnout. Social Work students must be provided learning opportunities that will enhance their knowledge regarding the important resources such as respite care, as well as advocacy and service organizations that are available to assist caregivers. They must be prepared to advocate for patients needs with doctors and other medical personnel, while ensuring that the older person (care recipient) is always a part of the decision making process.

Lastly, we must begin to acknowledge the importance of transitioning the role of caregivers to the next generation. The transmission of caregiving to the younger generation has been altered by the reality of numerous social contextual factors, such as grandmothers raising grandchildren (grandfamilies) and the cultural commitment and expectation to care for their own. However, without adequate socialization and support systems in place, they may not be prepared for assuming the role of primary caregiver (Wells-Willborn & Simpson, 2009). In summary, our work related to relative caregiving is not done yet.

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The author would like to acknowledge the hard work and dedication of Mr. Josh Spruill, Graduate Assistant at Florida Agricultural and Mechanical University, Department of Social Work for his assistance on this manuscript.