

# Relative Caregiving: Paying It Forward

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**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.