

Introduction to the Special Issue on Relative Caregiving

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

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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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