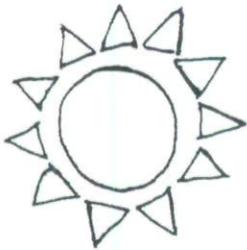


LONG-DISTANCE CAREGIVING: PERSONAL REALITIES AND PRACTICE IMPLICATIONS

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The National Council on Aging (NCOA) reported in 1997 that approximately seven million individuals were long-distance caregivers for older adults and projected that number to double within 15 years (Wagner, 1997). This article presents narrative profiles of two long-distance caregivers; the "lived experiences" of the authors examine common challenges of long-distance caregiving, compare aspects of the lived experience to data from national studies, and provides suggestions for long-distance caregivers and professionals who work with both care recipients and caregivers.



A study by the National Council on Aging reported approximately 6.7 million individuals were caregivers for older adults, usually relatives, living one hour or more travel time from the care recipient; the number of long-distance caregivers was projected to double within 15 years (Wagner, 1997). Family caregivers play "an invisible role...in our health care delivery system," especially for frail elderly individuals; families and friends provide over 80% of all informal and unpaid home-based care (National Family Caregivers Association, 2000, p. 2). We became members of this invisible caregiving population and part of the growing contingent of long-distance caregivers. Our "lived experiences" as long-distance caregivers were strikingly similar in many ways, yet quite different at the same time. In this article, we present a profile of long-distance caregivers from a national study and our individual stories, which focus on common challenges, what was unique in our situations, and aspects of our experiences that reflect the long-distance caregiving literature. We conclude with suggestions for long-distance caregivers and for professionals who work with both care recipients and caregivers.

Sharing personal stories, the lived experience, provides a deeper understanding about caregiving in ways that quantitative data cannot. Such narratives may normalize the experience of caregiving and provide ideas

for community resources and insights into the ways that others may think, feel, and respond in various situations. The story exchange also provides connections to others, the basis for social support. The caregiving experience takes on "personhood," moving beyond the caregiver and the care recipient, underscoring that these are individuals with complex roles and unique circumstances. Personal stories are particularly important to aspiring social workers who have not encountered similar situations either personally or professionally and can serve as springboards for reflection and analysis to blend the personal and interpersonal with literature on caregiving and eldercare at a distance.

Definition of Long-Distance Caregiving

While there is substantial research on caregiving in general, there has been relatively little focused specifically on long-distance caregiving (Metlife/National Alliance for Caregiving, 2004; Wagner, 1997). Most information on long-distance caregiving derives from the popular literature, which offers practical suggestions for these caregivers (e.g., AARP, 1994; Heath, 1993; numerous caregiving websites with "long-distance" links). It is important to recognize that long-distance caregiving is a term that has been conceptualized differently in the handful of existing studies. Schoonover, Brody, Hoffman, and Kleban (1988) studied parent

care and “geographically distant children.” They defined this population as those living “more than 50 miles” from their aging parents: “a threshold point at which visiting and face-to-face interaction between children and elderly parents decreases significantly” (p. 475). The National Council on Aging (NCOA) study of 200 long-distance caregiving adults defined the term as a distance of at least one hour travel time between caregiver and care receiver (Wagner, 1997). However, the NCOA study reported the average travel time was four hours, and the average distance was 304 miles. More recently, the MetLife/National Alliance for Caregiving (2004) survey of 1,130 long-distance caregivers reported the average travel time was over 7 hours and the average distance between caregiver and care receiver was 450 miles.

The National Alliance on Caregiving (NAC) and the American Association of Retired Persons (AARP) conducted a national study of 1509 caregiving adults, which included a question about travel time between caregiver and care recipient that ranged from living in the same household to over two hours apart. In our secondary analysis of the 1997 NAC/AARP data (Koerin & Harrigan, 2002), we identified 109 respondents who reported living more than two hours away. We selected this definition of long distance, i.e., more than two hours away, to more closely align with the NCOA study findings and to explore characteristics and experiences of caregivers who were the most geographically distant. Findings of these studies will be discussed later in relation to our own long-distance caregiving experiences.

The Good Daughter: Marcia’s Story

We are the typical U.S. family, scattered across many states but still connected by letters, cards, phone, visits, and e-mail. I am the 56-year-old “baby” of four and the only

girl. I live 500 miles from my hometown where my 92-year-old mother resides in a special care unit for persons with dementia. My twin brothers, five years my senior, also live in our hometown. Two of my mother’s four sisters live in my hometown, another sister lived there until her death two years ago, and the fourth sister lives in Tennessee. My parents raised my brothers and me in the house where she lived for 57 years, the last 15 years living alone after my father’s death. While getting from one side of town to the other demands only a 15-minute drive, my mother’s current residence in the nursing home is isolated socially and emotionally from the mainstream in which she had “swum” for 90 years.

Six years ago we four adult children together decided that our mother’s safety was at risk and that my brother David, the only one living in town at the time, should not have to carry the burden of care and concern because of the cognitive decline my mother was experiencing due to Alzheimer’s disease. She wanted to “age in place,” a typical desire of many elderly but not always wise. We demanded she move and mutually orchestrated when, where, and how. On the day of the move, we all were there to dismantle her home while trying to leave her sense of family intact. She joined in the hustle and bustle of packing by playing the piano and reminiscing of earlier years when it was our child voices that had streamed through the house.

Her first move was to an independent living apartment less than two miles away. After two years, her rising fears of night and being alone, plus her inability to manage the small 650 square foot apartment, put us into another tailspin. We knew her time was limited in independent living but so were the spaces in the special care unit in the newly built adjacent facility. Another collective decision was made, this time without our oldest brother who had recently died. We opted for the ability to choose the most desirable facility

versus bargaining for more time to avoid the inevitable move to a nursing home where a bed may not be available when needed.

What was the hardest day of my life? It was leaving my mother that first day in special care as she called my name and begged me not to do so, while at the same time I punched in the access code to open and then close the steel door between us. At that very moment her worst fear as well as my last wish came true. She was in a nursing home, separated from her family to whom she had devoted her life. And, I was the culprit because "I could have her come to live with me." Sure – 500 miles away from her sons, grandkids, friends, extended family, and even the several special-care nurses, some of whom were my high school friends. Yes, I fantasized that she could move in with us: my husband with a disabling condition, his 90-year-old mother, our two college-aged kids, one cat, one dog, and my full-time demanding career. No. It wouldn't work - whom was I kidding? Loss. Shock. Anger. Denial. Bargaining. These were familiar labels to my social worker self, but now they were only strong feelings that came again and again but never in order, and not at all pleasant. My mother's last home would be in special care and NOT with family. Local relatives visit weekly, and I drive or fly to Ohio at least every three months. I write to my mother weekly, have weekly contact with my local relatives, make periodic calls to the head nurse, and attend team care meetings as often as possible – this is the nature of my long-distance caregiving.

Once during a visit not long after this move, I asked my mom if she felt happy. Did she feel safe? Were people kind to her? These questions came easily but her expression led me to think the answers would not be so easy for her to say or for me to hear. To my surprise and relief *my* former caretaker emerged and replied, "Now, honey, this is a nice place and I don't want you to worry about me." The reply drove home the fact that, regardless of

what the future would hold, *she* would *always* be *my* mother. Nonetheless, the road to acceptance of this disease that was looting her personality bit by bit was a long, long journey for me that demanded my own reflection on the meaning of life's challenges.

Life is a series of change processes. As a young adult, I once asked an elderly woman who embodied what I thought was the pinnacle of success what her parenting goal had been for each of her five children. With little thought, she replied that it was to instill in each child the joy of handling the demands of life and to value the ability to do so even in the face of seemingly few rewards for doing so. So, unable to alter the course of a debilitating disease, my life circumstances, and my mother's living arrangement, I pondered what my mother had found to be most important in her life. It was family gatherings, travels shared with family and friends through daily postcards sent home, forwarding letters she received to other family members: in short, maintaining family ties by communicating events and arranging contacts with relatives and friends. It was at this point that I began to understand my role as a long-distance caregiving daughter: to help meet the needs that I believe my mother still has as a homemaker, mother, friend, grandmother – a family care taker.

It took some time for me to recognize this emerging theme in my role as long-distance caregiver. The main objective for my brothers and me was met: to ensure that our mother had good care in a facility that recognizes her present and past strengths and capacities. Our mother is well fed and clean, and the staff is interested in what she was and can continue to be. For example, once when I first arrived for a visit, an aide seemed particularly happy to see me. I soon realized she needed information: "Where was Vulcan Street?" she asked. You see, my mom grew up on Vulcan Street and it is there that she wants to return to at the end of each day in

the special care unit. She frequently describes her house while claiming that her parents are waiting up for her and she must get home. Her memory is so vivid and her enthusiasm so strong that two aides tried to find the street and house in this small town but to no avail. "Well," I tell them, "the house is no longer there; in fact, neither is Vulcan Street. It was taken out when the by-pass was built many years ago."

The reality of Vulcan Street is not what is important; what *is* important is that the people caring for my mother have listened to her stories and found meaning in them, and with her. They see her as a person of worth and dignity, a person with a past who can still find joy in the present. They find her to be fun and enjoy her playing the piano. When I bring in old pictures, such as my mom's high school graduation portrait or her wedding announcement, the residents and staff gather around to admire and imagine this small, blue-eyed, 92-year-old in her younger years. The staff provide professional and compassionate care that honors this person who has had a long and full life even when she becomes agitated over a small occurrence for no apparent reason. In turn, I recognize and encourage the importance of the care that staff provide, not only the medical aspects but also the tasks that address psychosocial needs. I believe that my experience as a social worker facilitates my helping and supporting staff when I am there, if only by being considerate in what, when, and how I make special requests. I try to pitch in by helping other residents file their nails, reading to them, and hearing their own stories.

With the most important objective met to ensure adequate physical care, another theme emerged from my role as long-distance caregiver: maintaining family contacts to preclude mother's isolation by promoting connection to those most important to her as she had done throughout her life. The first Christmas after my mother moved from the

family home, I wrote her Christmas letter to inform those who had sent her cards about where she was living and how she could be contacted. I forewarned that she might not recognize everyone who called but that the calls were important to her and our family. Many relatives and friends called me to convey their sadness about the move or to be reassured that she was in "a good place."

For my mother's 90th birthday, we honored her at our annual family picnic at my brother's home. I brought the family genogram on newsprint from a reunion held a few years earlier and invited everyone to add to the family history: marriages, births, deaths, and stories. I added my mother's pictorial "time line" that spanned her lifetime with pictures of as many family members as I could find. I posted selected pages from a diary of her senior year in high school right after her mother died, which detailed the surrogate mother role she acquired as the oldest child. Her sisters rested on every word in that diary that brought forth not only some sadness of that time period but more importantly the fact that my mother had so actively and willingly assumed the mother role: shoe shopping, dress making, and oversight of her sisters' homework. Not wanting the day to end, I reset her wristwatch, which she repeatedly checked to "be home on time," for two hours earlier to extend this family event. My mother enjoyed that birthday celebration, and the guests enjoyed watching her delight in familiar faces even though names and relationships at times were elusive.

While this situation seemed the best that was possible, my heart was not at peace. Perhaps out of guilt, but I think more so because as a social worker I am aware of the demands placed on those working in nursing homes in a managed care environment. I felt a need for my mom to have ongoing contact with a female family member. In spite of the excellent and fortunate care provided, it is not the same as "family" care, which would

provide favorite foods, mend clothes that are over-washed and dried, and do other caring tasks. But, why I felt this need was not immediately obvious to me; in fact, the mere thought provoked guilt. My brother more than met her needs and certainly handled all of the necessary appointments for dental, eye, and other care. He and my sister-in-law visited regularly and included my mother in family events whenever feasible, since her fear of dark precluded evening gatherings. Yet, I had lingering concerns: Was the care she received as adequate as it seemed when I visited? Why was there so much staff turnover? Were my aunt's complaints about my uncle's care in the same facility valid or applicable to my mother's care? Did she get the clothes that I mailed to her? Could my brother, who was not a social worker, know what to look for if there was insufficient care? I thought about hiring a care manager, someone to make a professional assessment, but that piece of my puzzle was not a snug fit. It had to be "Family." It needed to be a relative who had known my mother for a long time - but who?



My mother still speaks Hungarian, plays the piano and organ, and laughs, jokes, and makes silly faces with those inclined to be playful. I wanted someone to visit her who would know and could amplify these aspects of her life and do so regularly. I mentally considered everyone living close by and identified Linda, a first cousin, who was not employed. We had been close as children but had gone our separate ways as adults, particularly after both of us moved away. After Linda recently returned to the hometown to live only a block from my mother's house,

old family ties were rekindled, somewhat orchestrated at that time by my mother's sharing news of Linda's relocation. After a few months, my cousin Linda wrote to me to share her growing concern about my mother when she still lived in her own home. That was a brave but caring letter to write. But, how could I ask Linda to visit without insulting her or allowing her to say she was not interested? My only alternative was paid care/oversight. So, armed with the realization that I also could pay a family member, I made the job offer. To my delight it was accepted...and then some.

My cousin Linda began to visit my mother every Friday. At first she visited my mother alone, taking crafts, snacks, and magazines. When I was in town, she accompanied my mother and me on short trips to the store or to visit other relatives. Eventually, her visits to my mother frequently included her mother – Aunt Vi, my mother's youngest sister – and sometimes another of my mother's sisters, Aunt Liz.

Unfortunately, the checks I sent to my cousin were not cashed in spite of my pleas otherwise, if only so that I would have the freedom to make other requests of her. NO. Plain and simple, Linda would not accept money for what she thought was her family duty, however voluntary. But, there are other ways to thank a cousin who has written to me weekly to apprise me of my mother's status through reciprocal letters, gifts, and shared time when I visit my mother. Somewhat paradoxically, Alzheimer's disease, which left my mother unable to promote family ties as she used to do, has nurtured family relations as we siblings and cousins together lived our caregiving experiences.

The Good Daughter: Bev's Story

I became a care-anticipator years before becoming a long-distance caregiver. As the middle-aged only child of aging parents, I knew I would be responsible for assisting

them in getting the appropriate care they might need as their health and functioning changed over time. However, I had no clue about the tactical challenges and emotional distress I would experience in caring for my mother, who had Alzheimer's disease, and my father, who had had a series of small strokes. My parents resided in a city two hours away by car, where my husband's family also lived. We typically visited every couple of months and were in contact by phone on a weekly basis. As my parents became increasingly frail and vulnerable, I called and visited more often, ultimately calling daily and driving down almost every weekend in the several months prior to moving them to nursing care in my community. My goal had been to respect their desire to remain in their own home as long as possible and to involve them in decisions about other living arrangements if that became necessary.

My parents' health declines were gradual, but my mother's health became the first focus of concern for my father and me. In her mid-70's, she experienced circulatory problems that local specialists advised would require amputation of her leg. After consultations at hospitals in other states and several surgeries, the circulatory problem was resolved without amputation, but this health scare contributed to my mother's initial withdrawal; she seldom went out and had few contacts with family and friends. When she was 81, Mom had a heart attack and, at that point, her doctor indicated she was evidencing symptoms of hardening of the arteries. I noted some mild confusion, occasional inappropriate word choices, and increased irritability. However, I wondered whether these behaviors were related to the heart attack, new medications, and changes in routine at home upon discharge from the hospital with the employment of someone to do the cooking and housekeeping that mother had done for decades. I also knew that my mother's family history of depression should be taken into account, but that this was not a fact my parents acknowledged to

themselves, much less shared with their physicians. At that point, in the mid 1980s, I had little knowledge of Alzheimer's disease, and the same may have been true of the family physician, who did not suggest a neurological evaluation.

During my mother's illnesses, my father remained quite healthy and independent. He continued to work six days a week in the small retail business he owned until he was over 80. Even after retirement, he drove to the store a few mornings each week to handle advertising for the business and to socialize with employees and customers. His primary health problems were hearing impairment and minor strokes (TIAs), which affected his balance and gait. Dad was at a loss in dealing with mother's confusion, agitation, and mood changes and not able or willing to talk about his feelings and concerns, despite my broaching these topics and sharing my feelings of concern about *both* of them. As Mom's condition deteriorated such that she could not be left alone, Dad stopped going to the store and withdrew socially. He could not fully accept that she had Alzheimer's disease, even after diagnosis. He "covered" for mother by telling friends and family who called, including me, that she couldn't come to the phone and by discouraging visitors.

My caregiving experience was greatly influenced by our family norm of not sharing information that might cause worry or concern to other family members. For example, in their late 60's, both parents underwent surgeries without letting me know until after the fact because they didn't want to upset me. This pattern, in conjunction with distance and the gradual changes in their physical and cognitive functioning, made it difficult to determine when my help was needed – and what that help should be. On one visit related to mother's cataract surgery, I discovered that, although still verbal, she could not remember how to write her name on the medical consent form. On another visit, I asked my father about a

utility bill I found on the kitchen table and learned that he was no longer writing checks for household expenses; the accountant at his former business was taking care of that for him.

My parents were the last surviving siblings in their families, but they had several local nieces and nephews who kept in touch with my parents but were unable to share caregiving due to their full-time employment or failing health. Periodically, I would receive calls from cousins expressing their concerns following a visit to my parents and urging me to “do something.” I would also receive calls from the housekeeper, letting me know that my father had been slightly injured in a fall at home or that he had been in another minor automobile accident. At these times, I would “hit the road” again to see for myself how my parents were doing, to accompany them to doctors’ appointments, and to talk to Dad about his auto accidents, urging him to stop driving and providing him information about other transportation resources. My efforts oftentimes were met with their ambivalence and fears, disguised as resistance.

My social work background was quite useful in locating and negotiating services in the community that might be helpful to my parents and to me as a caregiver. I used the checklists and worksheets I obtained from the AARP to work with my father to get him to talk about and act on issues related to health care directives, power of attorney, and family finances. I brought brochures from the Alzheimer’s Association to help Dad understand that Mom’s agitation and combativeness were symptoms of the disease. At each step, I involved both parents, and later just my father, in decisions about health and/or social services; some they agreed to, and others not. I tried to help my father view these services as support for him as a caregiver – that these services would protect Mom if something happened to him and would ease my worries about them. In this way, I was

able to obtain services for both parents while reinforcing my father’s role as family caregiver and protector.

Arranging for services was easier than monitoring them, given my parents’ reluctance to having other people involved in their lives and my commitment to parental self-determination. In the year or so following her heart attack, Mom’s memory and speech problems became more apparent, accompanied by mood changes and an incident of wandering in the neighborhood. With my folks’ agreement, I contacted their new family physician to arrange an evaluation at the Geriatric Assessment Center of the local university hospital. Just before leaving to accompany them, Dad called to advise me that they had decided not to keep the appointment. A few months later I did go with them for an appointment with a neurologist to whom their family physician referred them, and this evaluation resulted in the probable diagnosis of Alzheimer’s disease.

As my mother’s need for assistance with Activities of Daily Living (ADL) increased, and as my father became less steady on his feet and less alert, we engaged additional in-home assistance. Theresa, the housekeeper who had worked for several of my cousins and whom we employed after my mother’s heart attack, became the on-site informal care manager for my folks. She worked half a day Mondays through Fridays, getting Mom up and dressed, making sure they had breakfast and lunch, seeing that my mother took her medications, and leaving dinners and weekend meals ready for Dad to microwave for himself and Mom. When Theresa noticed that meals were still in the refrigerator and Dad seemed to be having trouble getting mother into her bedclothes, she alerted me they needed someone in the evenings and on weekends. Dad was somewhat reluctant, partly due to expense and partly due to privacy concerns, but he agreed to the additional help. However, occasionally he

would decide they didn't need so much assistance and would "lay off" the weekend housekeeper. At that point, I would receive a call from Theresa or one of my cousins, asking me to intervene and insist on rehiring the weekend staff.

Dad agreed to several other services I arranged for, including an emergency medical alert system (call button and call box connected to a local hospital) and monthly geriatric case management visits from a Jewish Family Services' social worker. However, he would not consider adult day care for mother, and he stopped attending physical therapy and socialization events the social worker had arranged with his initial agreement. Nevertheless, having a social work case manager provided me with (1) a sense of security that a professional was checking in with my parents on a regular basis, (2) someone I could call in an emergency involving my parents, and (3) validation and support for me in my caregiver role.

As a long-distance caregiver, I experienced guilt about not being more physically available, grief over the loss of my mother as the disease progressed, and uncertainty as to whether I was doing the right things for my folks. With each visit, and in the summers when I stayed with my parents during Theresa's vacation week, I saw declines in my parents' functioning, assisted my mother with more ADLs (dressing, toileting, eating), and experienced their decreasing quality of life (from my perspective) that consisted mostly of dozing in front of the television in the dark, overly-heated den, with little social interaction or stimulation. Moving to their community, or uprooting them to live with me, were not options we seriously considered. In my mid 40's, I held a demanding full-time academic administration position, and my husband and I lived in a totally inaccessible house with three-stories and no first floor bed or bath. My parents had lived in their community for

most of their lives, and the one-story ranch house, their home for 40 years, was well suited for their needs as they aged in place. I also recalled my parents expressing their desire not to be "a burden" to me, given their experience as caregivers to my grandfather, who lived with us for seven years prior to his nursing home placement due to Alzheimer's disease.

I was plagued with fears about what was going to happen next and how to be ready for the next crisis. When the phone rang early or late, my stomach clutched in expectation that this was a call about one of my parents – a response reinforced by several such calls involving brief hospitalizations of one parent or the other. I visited every facility in my community and my parents' community, which had assisted living for my father and nursing care with an Alzheimer's unit for my mother. I knew they were at risk of falling at home, as both had done so several times. But they could just as easily fall in assisted living or a nursing home. In a congregate care facility, my parents might receive stimulation through social interaction and activities. But my parents valued their shared living space and their privacy, which would be severely compromised in nursing or assisted living settings.

I wondered to what extent my commitment to parental self-determination grew out of professional values as a social worker or personal difficulties in assuming a directive role with parents who had been dedicated to loving and protecting me, their only child. At what point did my desire/need to involve my father in planning and decision making cloud my judgment about his limitations in doing so? I consulted with social workers in geriatric care management in my parents' community and in my city to explore resources and to sort through the decision making process of planning for uncertainty. I received counseling to handle the anxiety and depression I experienced. Knowing that my

caregiving responsibilities would increase, I resigned my 12-month administrative position and took a more flexible 9-month teaching position. Ultimately, I did receive the call that I both feared and expected. My mother had been hospitalized after a fall at home and required nursing care upon discharge; this was the opportunity to help my father accept that Mom needed more care and protection than she could receive at home.

My long-distance caregiving lasted for about five years, followed by two years as a local caregiver. Once my father accepted my mother's need for ongoing nursing care, he wanted to be with her rather than home alone. Since they could not stay at home, he reasoned, they might just as well be in assisted living/nursing care closer to me. It took four months from my mother's hospitalization to get both of my parents into an appropriate facility in my community—obtaining required medical documentation, completing financial forms, getting on waiting lists, and bringing my Dad to visit the facility we had selected. Ultimately, however, the “best laid plans” did not materialize. By the time my mother's name was at the top of the wait-list, her condition had so deteriorated that she no longer met the Alzheimer's unit's requirements, and following another minor stroke, my Dad had been hospitalized and required skilled nursing care instead of assisted living care.

Such is life! We ended up with our second choice of facility where, within a short time, both parents were in the same room in intermediate-level nursing care. At that point, I assumed some of the responsibilities described in Marcia's story—dismantling and selling the family home, establishing relationships with nurses and aides, attending family care conferences, and bringing in old photographs and cakes/goodies to share with staff for my parents' birthdays and their 65th wedding anniversary. Mom died a year after her initial nursing home placement, and Dad survived a year and a half after my mother's

death. My conclusions, based on these experiences, are that caregiving is both painful and rewarding, whether long-distance or local, but that long-distance caregiving involves very unique challenges.

Profiles of the LD Caregivers, Care Receivers, and Care Networks

Our experiences were similar in many ways to those of respondents in our secondary data analysis (Koerin & Harrigan, 2002) of long-distance caregivers (N=109) in the 1997 NAC/AARP study. Most were women (56%), married (65%), ranging in age from 18 to 79, with an average age of 42 years. Like Marcia, the majority (51%) had children or grandchildren living with them at some point during the caregiving years. Over half (54%) worked full time as we did, and another 17% worked part time. Of those who had been employed while caregiving, 25% reported giving up work entirely, moving from full to part time, refusing a promotion, or taking early retirement. Over half of the long-distance caregivers provided care to a parent, and the most frequently reported conditions of the care receivers were aging (22%) and Alzheimer's/dementia (18%). Most long-distance caregivers (68%) reported someone else as the primary caregiver; they were often part of a larger care network, usually siblings. Consistent with Marcia's experiences, 65% of long-distance caregivers reported that other relatives did their fair share in care provision; 69% reported no family conflict over caregiving, and only 2% reported a lot of conflict. Unique to Bev's situation as an only adult child, there was limited family support.

The Challenges of Long-distance Caregiving

As our stories indicate, LD caregiving presents unique difficulties that are less frequently experienced by local family and friends providing care. Assessing the needs

of the care receiver and knowing when your help is needed from afar can be challenging when the care receiver experiences a gradual decline in functioning. While critical events, like hospitalizations or accidents, provide obvious indicators, some aging and/or ailing parents may not be able or willing to disclose information about their declining health status or care needs. They may want to protect their adult offspring from worry, inconvenience, or expense, while at the same time wanting to preserve their own independence; living at a distance offers this "protection."

On the other hand, care receivers, and sometimes their neighbors or local relatives, may contact the long-distance caregiver and provide an inaccurate and perhaps exaggerated account of the health and/or living situation. From a distance, it can be difficult to match what is reported (either positively or negatively) with the reality of the situation. Caregiving responsibilities in any situation may strain immediate and extended family relationships. Hooyman and Lustbader (1986) noted that local siblings often "resent out-of-town siblings for not doing more" (p. 51). While it is difficult for us to determine the extent of this resentment in our cases, we both encountered interactions with non-sibling relatives who were concerned about the care receiver and requested that we, as caregivers, "do something" about the situation.

Locating appropriate services and monitoring them can be problematic. A geriatric care manager can be an effective way to provide local oversight of services, as Bev's story reveals. However, geriatric case managers are not always available, and the cost (\$50-200 per hour) may preclude this option for those with limited income. Other financial costs may include long-distance calls, travel expenses, assistance with purchase of medical supplies and medications, and supplemental services. The MetLife study (2004) reported that long-distance caregivers

spend an average of \$392 per month in relation to their caregiving role.

Caregiver burden, which includes financial costs, has two dimensions: objective burden (time, efforts, tasks, financial supports) and subjective burden (perceptions, attitudes, emotions) that disrupt or change the caregiver's life situation (Biegel, 1995; Montgomery, Gonyea, & Hooyman, 1985). While some caregivers experience financial hardships or physical health declines, studies indicate that emotional strains are more prevalent (Brody, 1985). Experts have noted that "providing care for parents or elderly relatives nearby often is more physically exhausting than long-distance care, while long-distance care often causes more psychological stress" (Wagner, 1997, p. iii-5). We found that greater subjective burden, in contrast to objective burden, was supported by our study data and borne out in our situations. In identifying both burdens and benefits, long-distance caregivers in our study reported most frequently the same ones we experienced. As expected, distance from the care receiver, followed by the emotional strain of watching deterioration of their loved one, were the most frequently cited difficulties. The most frequently identified rewards included personal satisfaction, family loyalty, a sense of "giving back," and appreciation from the care receiver.

Summary and Recommendations

The long-distance caregiver plays a critical role in the care receiver's network by supporting local caregivers as well as by providing direct care. The National Council on Aging study (Wagner, 1997) and our study indicate a higher percentage than might be expected to have assumed or shared primary caregiver responsibilities. In the NCOA study, 21% reported themselves as the primary caregiver, with an additional 31% reporting equally shared responsibility (Wagner, 1997, p. 18). More recently, the MetLife study

(2004) reported 23% of long-distance caregivers were the “only or primary care provider” (p. 2). Our study revealed that nearly 11% provided primary care and another 21% shared care 50/50 with someone else (Koerin & Harrigan, 2002, p. 71). Thus, long-distance caregivers are often *not* secondary helpers, as might be assumed, given the distance between them and the care receivers. It is important for health and human service professionals to recognize and legitimize the role of long-distance caregivers as important members of the care network and not overlook or discount them. Normalizing the unique experience and supporting these long-distance caregivers in their efforts may help to reduce caregiver stress and guilt related to not being more physically accessible to the care receiver. We have several recommendations for long-distance caregivers and the professionals who work with them, based on the literature and our experiences:

- Don’t minimize or negate the needs of the long-distance caregiver and the importance of that role;
- Recognize caregiving stress and promote self-care;
- Don’t assume that everyone in the caregiving network is equally informed about the care receiver and his/her needs;
- Seek and consider *all* sources of information to minimize misrepresentation or misunderstanding of the care receiver’s situation;
- Don’t carry the burden alone – think systemically about what others can provide;
- Don’t avoid sharing care responsibilities with other family members due to fear of potential conflict;
- Help others be caregivers by suggesting what they can do to help the care recipient, you, or other caregivers, and accept the care that is freely offered;
- Think creatively to enhance the lives of loved ones: there is nothing too novel, silly, or sentimental if it brings comfort to others;
- Consider new technologies such as a telephone dial pad with pictures of persons whose numbers are keyed in or live audio-visual interaction using the Internet;
- Support the local caregivers and recognize the roles that everyone plays to provide care;
- Be sensitive to the situation of local caregivers who must make immediate decisions that may not be the same as those you might make;
- Use the situation to “let go” of old family conflicts and contribute to family continuity and cohesion;
- Don’t assume you know the local resources even if the care recipient is living in your former hometown or residence;
- For social work or health care professionals who are caregiving, use your professional knowledge and skills to navigate the caregiving network and do not alienate others by dominating, being “the expert,” or expecting perfection;
- Strive for perspective; your caregiving role is not forever.

There is no single profile of the long-distance caregiver, and the demographics continue to change, such as the increase in

male caregivers. In our mobile society, the need for local and long-distance caregivers has never been greater. The need for a broad range of options to provide caregiving also has never been greater.

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