

THE PATH OF CAREGIVING: FROM FAMILY CAREGIVING TO SUPPORTING AND GIVING VOICE TO THOSE WHO PROVIDE CARE TO LOVED ONES

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This narrative focuses on the author's path of caregiving, including her early family experiences as a caregiver for an elderly grandparent with dementia. This personal experience fueled her desire to work with caregivers as a medical social worker in a home health setting. This path of caregiving was continued when she conducted her dissertation research on caregiving among older, same-sex couples. Through these personal and professional experiences, the author developed astute insight into the challenges and rewards of caregiving, and also provided essential education about the supports that are needed (at the personal and policy levels) to sustain the caregivers.

The Personal Path: A Life before Dementia

This is a story of three generations of women and one life-altering experience that they shared. To understand this experience, it is imperative to provide a brief account of my grandmother's life before the onset of dementia. Anne Barry was born on October 19, 1900, as the only child of Daniel and Anna (of Irish and German descent) and was raised to be a proper, middle-class, Philadelphia lady. She completed twelve years of formal education and was voted "best looking" by her graduating class. After high school she held various secretarial and training positions. She married Joseph Smith, an engineer, in 1937, and his job relocated the couple to Ohio. In 1938 they welcomed their first and only child, Anne. Anne (my mother) was always closer to her father and was his constant companion at football games and in fixing things around the house. This closeness to her father seemed to only distance my mother from my grandmother and created somewhat of a competition between the two ladies.

Like many women of her cohort, Anne never learned to drive. She appreciated a good Latin Mass and the Ave Maria and despite her general conservatism, she loved the television show "Three's Company." Black coffee and jelly donuts were her food and drink of choice and she made no excuses about her use of cake mixes and other conveniences over cooking from scratch. Her avid reading, passion for crossword puzzles, and constant

correcting of the grammar of others led some to believe she was a retired English teacher.

During the 1960s, Anne and Joe Smith became grandparents to David, Daniel, Amy, and Kristina. At that point her AKA (also known as) became "Granny." In 1971, she lost Joe as a result of a stroke. She never remarried but did not live alone after my grandfather died. My mother, siblings, and I moved into my grandparents' house one year later when I was four. Nothing in Granny's life had prepared her for living with the "shenanigans" of my three teenage siblings. In particular, she was subjected to Dann's pranks, which included his calling her, pretending to be department store security staff who had detained her grandson for charging several thousand dollars to her account. Distraught by the unsightly appearance of Amy's bedroom, she swore on several occasions that when she died, she wanted a special "peep-hole" in the clouds to look down on Amy and her family to see if her adult home was kept any better.

As my teenage siblings were challenging her values and keeping her young, Granny was very much my caregiver in childhood. She walked me to school on my first day of kindergarten and sat nervously on a bench during my first swimming lesson. In the morning she brushed and braided my tangled hair and chased me into the bathtub at night. She sent me to the corner store for candy and gave me change for the ice cream truck. She rubbed my back every night to put me to sleep. Despite her dismay with my tomboyish behavior, she repeatedly told me I was the

"best little girl in the world." Little did I know that I would have the opportunity to return the care she gave to me.

The Path Begins

When my parents relocated to Iowa in the early 80s, Granny lived with us briefly, but then rented an apartment near my high school. A few years later we began to suspect that Granny was having problems with her memory. She began to burn coffee pots, bathed less frequently, and forgot to take her medicines. After being hospitalized for water retention, it was decided that she should recover at our house since my mother was a nurse and my father was a physician. As her care needs increased, she eventually gave up her apartment and became a full-time occupant at our house. I was in high school and the only child still in the house.

At first, I did not know what to make of Granny's illness or the situation. Looking back, I cannot recall anyone else that I knew whose family was caring for an older relative at home. She became increasingly confused and disoriented to time and place and would frequently ask, "Where am I?" I sometimes found her behavior to be embarrassing, especially when my friends were around. She also began to seclude herself in her room when we would have company; I think she, too, was embarrassed by her condition. It became necessary to safety-proof the house; we removed the knobs from the stove to keep Granny from turning it on and removed the coffee pot from the kitchen. She began to sleep most of the day and sundown (wander) at night. Through this, our dog, Tess, was her constant companion, keeping her feet warm during the day and walking beside her at night. Although I am now aware of the therapeutic benefits of pets for persons with dementia (Churchill, Safaoui, McCabe, & Baun, 1999), I'm ashamed that during that time Tess was more understanding of her situation and more responsive to her needs than I. It wasn't until I was called upon to help with feeding and bathing that I really understood her condition and appreciated the opportunity to return the care Granny had given to me.

In contrast, the progression of Granny's illness only further strained the relationship between her and my mother. Once Granny's inhibitions subsided, she could be combative, and she often uttered hurtful words to my mother. While I was able to convince her to get into the bathtub, she would sometimes take swings at my mother when she attempted the same task. Being an only child, working full time, attending graduate school, and raising a teenager, on top of serving as a caregiver, my mother was the picture of the "woman in the middle," trying to balance these responsibilities.

Despite the challenging aspects of the experience, it is the humorous events that I choose to revisit most often this decade later. Granny's sundowning involved pacing but also snacking throughout the night. My two most vivid recollections are the night she ate the entire top row of a box of Whitman Sampler candy (her favorite) and the night she ate an entire pie. When asked, she would always suggest that the food consumption was the work of someone else. Tess was blamed for polishing off the pie and my brother Dann, who would have been a likely suspect had he not been away at college, for devouring the candy. During this time my mom and I couldn't help but think, "Wouldn't it be great to be able to eat an entire pie, not feel guilty because you don't remember eating it, and not gain a pound because you have walked it off?"

Following Granny's hospitalization in 1990 for water retention and congestive heart failure, my parents decided that it was no longer safe for Granny to reside in our home and that she needed skilled nursing care. As many know, caregiving does not end when a loved one enters a facility. I became a familiar face around the facility and tried to arrive during mealtimes to be sure she was actually eating from the tray they left in front of her. She was not a big fan of yogurt, but I discovered that she would eat it if it was lemon flavored and I told her it was lemon meringue pie. Deceitful? Maybe, but necessary given her rapid drop in weight and questionable nutrition. I would also make sure she was wearing clean (and her own) clothes and that her glasses, as well as a box of chocolates, were within her reach. Her weight was not my only care concern. Due to

what I know now are the realities of nursing care facilities, I was amazed by her loss of individuality and the assembly line way in which she was treated. I arrived one day to find her hair in pigtails and ribbons, by which she would have been utterly horrified. Her television would always be blaring something other than her beloved soap operas and coffee was only offered once in the morning.

On May 27, 1991, the nursing home called my mother to tell her that my grandmother was dying of congestive heart failure. During the past few weeks she had eaten less and less. Standing by her bedside, my mom and I sobbed as we realized that this was it. Because she did not have the energy to sip, I placed drops of water on her tongue. My mom changed her undergarment and cleaned her. For the first time I knew that this is what dying looked like and what losing someone you loved felt like. Just then my mom took her mother's hand, leaned over, and said, "It's OK, go and be with Dad." Later that night, when I was sleeping, I faintly heard the phone ring. More than half asleep, I could feel something lightly touching my back. In the morning my mom told me what I somehow already knew: Granny had passed.

The Path Continues

The experience of caregiving touched my life in infinite ways, one of which is professional. I knew toward the end of my caregiving experience that I wanted to learn more about aging and families' coping with the needs of older loved ones. During my undergraduate years I sought out aging-focused or related courses in college and specialized in gerontology, and I worked as a graduate assistant in the Center on Aging during my MSW program, writing papers about dementia and/or family caregiving when given the chance during both of these educational experiences.

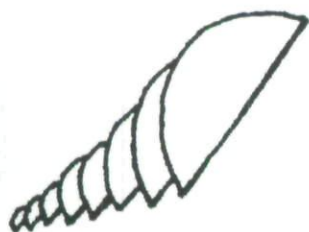
My post-MSW practice experience involved a position as a medical social worker for a home health-care agency. The service area included a mixture of urban and rural areas. The majority of my clients were older adults; many suffered from one or more chronic illnesses and required assistance with

activities of daily living (ADLs), such as assistance with feeding, toileting, and bathing. Many received full- or part-time ADL assistance from family members.

In this position, I was able to see and intervene in the day-to-day problems of the chronically ill and their care-providers. These problems often involved a lack of resources, both human and financial. The need for hands-on care and transportation often surpassed the friends, relatives, and community social services available to meet these needs. The household bills, compounded by the rising costs of needed medications, left many older adults with only pocket change at the end of the month. Acquiring supports that would allow individuals to stay in their homes was never an easy task, and case management often felt like putting a band-aid on a situation that required a cast.

Older clients in rural areas appeared to have an advantage over their urban counterparts, as many lived close to family members. It was not uncommon for three generations to live within a mile of each other. This worked amazingly well when it came to caregiving. Often, the client would remain independent in his/her own home, while children and grandchildren took turns cooking meals and providing transportation. With the growing mobility of today's population, living near and receiving care from family members becomes less feasible for many older adults. For this reason, coordination with families across the miles became increasingly more common in this position. This across-the-miles or "long-distance" caregiving was also gaining national attention and was experienced by some seven million Americans (National Council on Aging, 1997).

Resource gathering and coordination was a daily activity in this position. The most difficult responsibility, though, was introducing the topic of institutionalization. Because of my previous caregiving experience, I was sensitive to the physical and emotional strain of providing care and always discussed this option with caregivers. Unfortunately, families often avoid the topic of long-term planning and possible placement, as no one wants to see his/her loved one in a nursing home. Likewise, promises



were often made to never send the loved one to a nursing home. As a result, placements were often made at the absolute breaking point and usually after a hospital stay. In this case, families had less than adequate time to find the optimal setting for their loved one. At this point, families often felt that they were committing the ultimate betrayal and were left feeling extremely guilty.

My personal and work experience related to caregiving fueled a desire to conduct research in this area. Because I wanted to do research and teach, I enrolled in a Ph.D. program in social work. During my first semester I became interested in the experiences of non-traditional caregivers, those whose voices were not often heard in the traditional caregiving studies. Discovering a major gap in the literature and for personal reasons, I narrowed my focus to midlife and older (50+) gay men and lesbians who provide or who had provided care to same-sex partners. This became the topic of my dissertation in which I conducted qualitative interviews to uncover the unique experiences of these often-hidden caregivers (Hash, 2006).

During this research, I was fortunate to encounter 19 wonderful individuals who were willing to share their remarkable stories. They ranged in ages from 50-77. What I discovered through this study was that gay and lesbian caregivers experience many of the same strains as traditional caregivers, including exhaustion, decreased finances, conflicts with employment responsibilities, and emotional strain (Cantor, 1983; Poulshock & Deimling, 1984; Shultz, Visintainer, & Williamson, 1990; Zarit, Reever, & Bach-Peterson, 1980). The unique aspects of their experiences, though, involved their interactions with informal (family, friends, coworkers) and formal (health care and other professionals) support persons and services and their long-term planning and decision-making processes. Persons outside of the partner relationship had the potential to greatly affect the caregiving experiences. Respondents were often faced with informal support persons who were not accepting of their partner relationship. As a result, some of their family and coworkers did not acknowledge the relationship or provide the

level of support needed during caregiving or bereavement. Ex-spouses and adult children, in some cases, were particularly hostile toward the couple and the caregiver. Heterosexual couples in this situation do not often face this type of treatment and discrimination by others. Despite family and coworkers, who were unsupportive, some had the advantage of a strong network of friends and family members who were supportive of the partner relationship.

Although homophobic attitudes were not often overtly expressed by professionals, they were many times apparent through slighting remarks or rude or hostile behavior on the part of professionals. A few respondents mentioned staff that gave them "dirty looks," were "uneasy" or "un-engaging" or "acted like they didn't want anything to do with gay patients." A particularly upsetting occurrence involved a nursing assistant asking a patient's elderly mother whether her son was the "husband or the wife" in his relationship with his same-sex partner. Some policies and practices were also insensitive to same-sex partners, often insisting that the "next of kin" was not a partner. Although some poor treatment was attributed to homophobia, much was seen as the result of a health-care system that has become far too impersonal. Respondents described supportive professionals as those who were supportive and respectful of the partner relationship and those who referred the respondents to other supportive professionals and services. At times, these professionals also bent the rules and treated partners as immediate family as far as policies and decision making were concerned. Unfortunately, respondents expected to be faced with insensitive professionals and individuals because of their sexual orientation.

In many ways, the long-term plans and decisions made by the couple and the caregiver appeared to be very different from those of their heterosexual counterparts. Although many couples set up advanced directive documents that stated their medical and financial wishes, the reasons the respondents and their partners drafted these documents are seemingly very different. Many set up advanced directives to ensure that their wishes

would be protected within health care and other settings. This included living wills that stated the measures to be used to keep the individual alive and powers of attorney which designated a partner as the primary financial and medical decision maker should the individual become incapacitated. For some, this was based on fear that their family members would try to interfere with their plans. Additionally, some used advanced directives to clarify the nature of their relationship and their wishes to health-care professionals. The intention was that if a partner's name was listed as a power of attorney and primary decision maker, a professional would understand that this was the most important person in an individual's life. There was also great variety in the arrangements of finances and property ownership among the respondents and their partners. Some owned property and held finances jointly, while others kept finances completely separate. Still others had a mixture of shared and separate property and finances. As far as their own long-term plans, several respondents voiced concern over who would be available should they need care in the future. Very few felt that they could rely upon a circle of friends for assistance and many feared harsh and hateful attitudes and behaviors they would encounter (as a gay man or lesbian) should they need skilled nursing care.

The Path Comes Full Circle

Following the completion of my Ph.D., I started a position as an assistant professor in the department where I received my MSW and had held my first professional social work position. In this position, I continued to focus my research and teaching efforts on caregiving and aging. My training in the Ph.D. program had prepared me to meet the expectations of an academic career. Granny had prepared me for the transition that would come next, that of a parent.

The challenge of raising dogs was significant but that of raising a child would be momentous. Given my poorly behaved dogs, I wondered if I had what it takes to be a good parent. Our daughter is two years old and I

now know that "what it takes" to be a parent changes on a daily basis. Her first six months I spent taking care of her during the day and teaching courses at night. In that time I became much more proficient in diaper changing and baby handling. Believe me, I had a long way to go in terms of proficiency. By the end of the spring semester, we were a finely tuned mother and daughter daytime team. While bathing and dressing her, I sometimes think about Granny and how she had done the same for me when I was a child. My thoughts then turn to how I was able to return this very care when Granny needed me the most.

The path has come full circle now, and I am building upon the love and care Granny and I shared as I nurture and care for my daughter. The patience and sense of humor I honed while providing care to Granny have served me well in caring for the next generation. I marvel at my daughter's growth and cherish the opportunity to care for her and contribute to the beautiful little person she is becoming. I am convinced that my daughter is "the best little girl in the world" and I fear that our walk to kindergarten will come much too soon. When that walk comes, I will show her the photograph of Granny and me on the front porch before heading off to my first day of school.

Implications

I still have the *Newsweek* magazine whose cover study focused on women in the middle and family caregiving for older adults (Beck, Kantrowitz, Gordon, Roberts, & Hammill, 1990). That was the first time I had seen the popular media tackle this subject. Twenty years later, the general public is well versed in this phenomenon. Despite the increased visibility, providing care for older loved ones and keeping them in the home remains one of the biggest challenges faced by our nation. Through my personal experience as a caregiver, as well as my educational work and research endeavors, I have developed certain insights into the present and future of caregiving for older adults. These insights can best be explained as implications for research in this area, policies and services, and health and human service professionals.

Research on Caregiving

The family caregiving literature has been rapidly growing since the late 1970s and has contributed greatly to the understanding of the caregiving experience for people with Alzheimer's disease and related dementias. In general, these studies have shown caregiving to be a very challenging role, one that is physically, emotionally, and financially taxing for families (Cantor, 1983; Cuijpers, 2005; Poulshock & Deimling, 1984; Vitaliano, Zhang, & Scanlan, 2003). Despite these adverse effects, research has also shown positive outcomes of caregiving, including a sense of pride in providing care and the ability to keep loved ones in the home environment (Farran, Keane-Hagerty, Sallowat, Kupferer, & Wilken, 1991).

The majority of these studies have focused on the experiences of the "primary" caregiver and the care of older family members. This person is described as the person who assumes most of the caregiving responsibilities (Baum & Page, 1991). The primary caregiver is often a spouse. In the absence of a spouse who can provide care, an adult daughter or daughter-in-law typically assumes the role (Cantor, 1983; Stone, Cafferata, & Sangl, 1987). As primary caregivers, adult daughters and daughters-in-law often become "women in the middle," caring for ailing parents while also caring for and raising children and working outside the home (Brody, 1981).

Very few studies have looked at the experiences of secondary caregivers, or those who do not have primary responsibility but who also provide ongoing assistance (Bedard, Raney, Molloy, Lever, Pedlar, & Dubois, 2001; Tennstedt, McKinlay, & Sullivan, 1989). Compared to primary caregivers, secondary caregivers are younger (often adult children), report less burden, often do not live with the care-recipient, and provide fewer hours of hands-on care (Bedard, Raney, Molloy, Lever, Pedlar, & Dubois, 2001; Tennstedt, McKinlay, & Sullivan, 1989). Tennstedt et al found that secondary caregivers are more involved in supplemental and instrumental tasks, such as shopping and transportation. They also provide a great deal of emotional support to the primary caregiver (Bedard et al, 2001; Tennstedt,

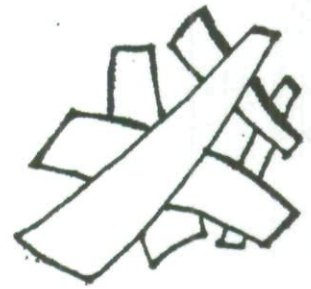
McKinlay, & Sullivan, 1989). Because of their instrumental role in the caregiving situation, future studies should further investigate the role of secondary caregivers and the special challenges they face.

Secondary caregivers are not the only persons whose experiences are largely invisible in the caregiving literature. The experiences of minority and non-traditional caregivers deserve much more attention. Fortunately, the unique experiences of ethnic minority caregivers (Chun, Knight, & Youn, 2007; John, Hennessy, Dyeson, & Garrett, 2001; John & McMillian, 1998; Mahoney, Cloutterbuck, Neary, & Lin, 2005) and male caregivers (Kaye & Applegate, 1990) have been given increased consideration in the recent years. The experiences of sexual minorities are still hidden from view. The model of family caregiving should continue to expand by including the voices of ethnic and cultural minority caregivers. Reliance on the traditional model of caregiving can only adversely affect the policies created for and services rendered to caregivers and care-recipients.

Policies and Services

The advantages of home versus institutional care are quite evident. In the interest of containing state and federal healthcare spending, homecare provided by informal support persons is far more cost effective than the average yearly nursing home cost of \$60,000 per resident (MetLife, 2004).

Caregivers, then, are clearly the best defense against the rising costs of institutional care and the strain those costs place upon the Medicare and Medicaid systems. Not only is homecare cost effective, but it is also preferred by older adults and their loved ones. In addition, future demographics will likely lead to fewer available caregivers for chronically ill older adults due to the graying of the "baby-boom" generation and the shrinking sizes of American families (International Longevity Center & Schmieding Center for Senior Health and Education, 2006). For fiscal as well as compassionate reasons, when one or more individuals are willing to provide in-home care to an older adult, we need to do everything in our power to sustain them and the situation.



This cannot be accomplished while Medicare and Medicaid continually cut funding for homecare services. To sustain homecare situations, the Medicare and Medicaid programs will need to re-commit funding for local services that provide in-home medical and respite services.

In addition to increased funding for in-home services, supporting and sustaining caregiving situations will require a re-conceptualization of what we now consider "family caregivers." This will need to be accomplished by federal and state policy makers as well as administrators of local health and human service organizations. Recognizing same-sex couples as legal partners would go a long way in supporting gay and lesbian caregivers. The enactment of such a policy at the federal level would logically lead to Social Security benefits, provision of tax benefits for in-home caregiving, paid leaves of absence at places of employment, and equality in health insurance policies. At the local service level, hospitals and other organizations should include same-sex partners as "next of kin" on their forms and procedures. As a term, "next of kin" should be replaced by "primary contact person," which would allow a client or patient to designate the person who provides care and/or who is dearest to them. For many, this may not include blood relatives, but instead, friends and neighbors. Expanding our concept of family at the policy and organizational levels can only increase the support to diverse caregivers.

Health and Human Service Professionals

One of the simplest, as well as most important, ways to support caregivers is to recognize the care they provide and praise them for taking on one of life's most difficult tasks. Health and human service professionals should never forget that caregiving is a life altering experience; thus they should convey empathy for those who take on the caregiver role. In addition, encouraging caregivers to talk about the positive aspects (including humorous events) of their experiences and the meaning the role has brought to their lives is an important but often neglected aspect of communication (Farran et al, 1991; Hash, 2006; Sanders,

2005). Also critical is letting caregivers discuss their feelings of strain and guilt and reminding them to take care of themselves and each other. It is often helpful to promote the view that they need to take care of themselves before they can fully take care of someone else. The analogy of airline emergency procedure announcements can illustrate this point: "If you are traveling with [someone vulnerable], in case of emergency, place your oxygen mask on first before assisting the other person."

In addition to encouraging caregivers to take care of themselves, health and human service professionals should engage caregivers as well as themselves in burnout prevention. This can be accomplished by resource planning and discussing long-term plans with both caregiver and receiver (Whitlatch, Judge, Zarit, & Femia, 2006). Caregivers need to plan for the time when they can no longer provide in-home care and professionals need to provide information on alternatives and be ready to support caregivers through such a process.

Together with recognizing their efforts and encouraging long-term planning among caregivers, professionals should think outside of the box in assessing caregiving situations and informal supports. In assessment it is important not only to look at present family dynamics but also to identify the history between family members. In my caregiving experience, the situation was exacerbated by a mother-daughter relationship that had been strained for many years prior to the onset of care. The role of secondary caregivers should also be considered in assessment, especially since these persons often serve as emotional supports for the primary caregiver. Thus, sustaining secondary caregivers is equally important. Thinking outside of the box also means understanding the unique needs and experiences of diverse caregivers, including friends and neighbors, same-sex partners, men, and ethnic minorities (Dilworth-Anderson, Williams, & Gibson, 2002; Hash, 2006; Himes & Reidy, 2000).

Professionals and educators in health and human services have an additional and ever-increasing challenge in meeting the needs of caregivers and care-recipients. A growing

number of social workers, nurses, and physicians will be needed to meet the needs of a rising population of older adults with chronic illnesses. The critical need for geriatric social workers in particular has been widely noted in the literature (Berkman, Gardner, Zodikoff, & Harootyan, 2006; Scharlach, Damron-Rodriguez, Robinson, & Feldman, 2000). Professions and educational programs will need to increase their efforts and investment in geriatric education and training. Dramatically increasing the number of educational courses related to aging, caregiving, and health care would be a step in the right direction. Professional visibility and organization will also be required to actively recruit individuals to work and study in this area. In addition to these professional and educational efforts, I anticipate that others (like me) will be drawn to work with and on behalf of older adults and caregivers through personal life experiences. Given my experience, I hope that Granny has found that peep-hole in the clouds and can see not only that Amy's home is tidy but also that her involvement in my life and the opportunity to care for her has shaped my life.

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