

Chapter 2

Family Caregiving: Implications for Rural Practice, Policy, Education, and Research

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Societal norms for family solidarity, and reciprocity and the shared belief that kin can, should, and will depend on each other provide strong social imperatives for families to care for kin in times of sickness and disability (George, 1986). Of the 44 million Americans who provide unpaid, informal care for someone with a chronic illness or disability, more than 80% are family kin: spouses, adult children, grandchildren, or others related by blood or marriage to the person for whom they provide care (National Alliance for Caregiving and AARP, 2005; Pinquart & Sorensen, 2006). However, family caregiving has been associated with burden, caregiver role strain, and distress (c.f. Berg-Weger et al., 2000; Schulz & Beach, 1999) and family care can be particularly stressful in rural communities where kin often do not live together. The intent of this chapter is to describe the challenges of rural caregiving and discuss selected research findings around three caregiving issues that have practice, research, training, and policy implications for helping families care for rural kin: *caregiving and family functioning, family caregiver assistance, and finding meaning in family care.*

The Challenges of Demography

Sixty-five million Americans live in rural areas and almost half of them are over 50 years of age. Thus, a predominant topic of concern in rural areas is caregiving for rural elders and their family caregivers. Elders in rural areas are more likely to live alone, live in or near poverty level, and suffer from more chronic disease and physical disabilities than their urban counterparts. At the same time, the rural elderly have

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less access to local health care (U.S. Department of Health and Human Services Rural Task Force, 2002), and require more travel (an average of 46 miles) to see a health professional (HHS Rural Task Force Report). In the face of higher incidences of acute and chronic disease, fewer local health-care resources and the prevailing societal norms that family members will serve as primary caregivers, rural elders generally depend on their family members for informal care (HHS, 2003). Population migration trends reveal the movement of younger generations from rural to urban areas in search of lifestyle supports and employment. When elder family members remain in rural communities, caregiving takes on the added dimension of distance. Thus, the first challenge is to address how family caregiving can be effectively provided at a distance.

Between 3 and 6 million Americans are distance caregivers for elders, family members who live an average of 450 miles away, and travel more than 14 h round-trip to participate in the elder's care. Based on a national survey of more than 1,000 informal caregivers, the typical distance caregiver is a 46-year-old married woman who is employed outside the home and cares for her own nuclear family while providing care for her widowed mother who lives alone. When conflicting work or family responsibilities make it impossible to give care, she cobbles together various unpaid and paid assistance for her mother that costs, on average, \$437 dollars each month (National Alliance for Caregiving and AARP, 2005). While the traditional perspective of informal caregiving has been that of a single, primary caregiver, evolving profiles of the American family have changed this view. A second major challenge involves the family caregiver's management of multiple, competing demands.

Because families in both rural and urban communities are smaller in size and are more likely to include kin who are full-time wage earners (U.S. Census Bureau, 2002), rural caregiving also may involve "fictive" kin as well as a number of blood kin. Fictive kin are individuals who have strong interpersonal, social, and or geographic ties to the elder, but are not related by blood or marriage (Jordan-Marsh & Harden, 2005). For example, fictive kin caregivers might include the elder's neighbors, church members, postal and public agency representatives. From her interviews of 114 fictive kin caregivers caring for frail elders in the community, Barker (2002) reported that almost half of these fictive kin caregivers were themselves older adults who felt morally obligated to help other elders with tasks of daily life. Thus, a third major challenge involves building elder care networks in rural communities that extend beyond blood relations to include others who participate in the delivery of informal care.

The Challenges of Informal/Family Care

Among the descriptions of informal or family caregiving, one has sustained the test of time. More than 20 years ago, Horowitz (1985) categorized informal care as involving four dimensions: *direct care* (providing assistance with bathing,

dressing, managing medications); *emotional care* (providing social support and encouragement); *mediation care* (negotiating with others on behalf of the care recipient); and *financial care* (through gifts or service purchases). The challenges of actually providing informal caregiving have been attributed to: the level of intensity and physical intimacy required to provide care (Montgomery et al., 1985); the amount of burden, distress, and role strain that care engenders for the caregiver (Aneshensel et al., 1993; Berg-Weger et al., 2000; Seltzer & Li, 2000); and, the skill required to master care tasks (Schumacher et al., 2000).

Family caregiving for a frail elder reflects these challenges. For an elder, informal care usually is initiated around the tasks of daily life such as helping with meal preparation, housekeeping, household maintenance, and transportation. Recognizing that elders often have at least one chronic condition, the management of the chronic disease regimen adds varying degrees of complexity to these tasks. Over time, the elder's need for assistance progresses to help with personal self-care tasks such as eating, bathing, mobility, dressing, and toileting. These tasks are more intense and are far more challenging when the caregiver has other demands, personal health problems of their own, and lives away from the elder's rural residence.

Current Status

A variety of demographic and situational factors have been reported to influence informal care outcomes, including the nature and progression of the elder's illness/disease (e.g., unexpected or rapid onset, downward trajectory), specific care requirements (management of confusion, behavioral problems, incontinence), and the nature and scope of support and assistance provided by others. Caregiver and care recipient characteristics (age, gender, ethnicity, education, health status, life stage) also influence care outcomes (Seltzer & Li, 2000; Schulz & Beach, 1999; Pinquart & Sorensen, 2006; Schulz et al., 2006; Sherwood et al., 2005), but perhaps none so strongly as the nature and quality of the family relationship. Spousal caregivers are at greater risk for personal health problems and role overload than adult child caregivers; adult child caregivers express more negative feelings about the demands of caregiving, possibly because of the demands of care on their lives or possibly because of the impact of caregiving on family functioning (Davis, 1997; King et al., 2002; Sparks et al., 1998; Yee & Schulz, 2000).

Caregiving and Family Functioning

Families influence caregiving and family life, in turn, is influenced by caregiving. Why some families struggle and others thrive, is unclear. Over time, families develop roles, patterns of communication, and rules for behavior. This stability serves the

family well in times of predictable life transitions such as childbirth, children's entry and exit from school, leaving the parental home, and retirement. Caregiving presents an unexpected and often unanticipated transition over an uncertain period of time, for which there seldom are clearly defined roles, communication patterns or rules. Bourgeois et al. (1996) noted that intra-familial conflicts around care are common. They compared parallel assessments of two caregivers of kin with Alzheimer's disease. They explored divergent views about kin problem behaviors, primary caregiver strain, and caregiving efficacy. Agreements were greatest around kin behavior problems and disagreements were greatest around primary caregiver coping abilities. These differences were strongest among female–female caregivers.

Families who successfully cope with caregiving likely are those with good problem-solving skills, who can communicate well during stressful periods, and who can make sound decisions during periods of uncertain change. Designation of the primary family caregiver is one of the first care decisions families must make. Although this might be more obvious for family members caring for a child, the identification of who will serve in this capacity for the care of an elder family member is often driven by ethnic custom or family history. This first decision is also one that can begin to put the elder, the family, and the informal caregiver at risk for future difficulty. Primary caregivers typically function as case managers as well as care providers: coordinating the care of others as well as personally providing care. Other care providers function as secondary and auxiliary support, assisting with care services under the direction of the primary caregiver (Usita et al., 2004). For instance, a caregiving husband might manage household finances and help his dependent spouse with meals but delegate his wife's personal hygiene care to their two daughters. Or an adult daughter might provide direct care for their father but expect her brother to provide financial assistance and mediate with agency representatives regarding their father's insurance and pension issues. In a rural community, a distant family caregiver might provide transportation for her elderly father's regularly scheduled monthly doctor's appointments, but depend on a neighbor to make sure father takes his medications each day.

Regardless of the care model, when family caregivers do not fulfill their expected care responsibilities, family norms for solidarity and reciprocity are challenged. In such cases, interfamilial conflicts may develop between various stakeholders: between the care recipient and caregiver, between primary and secondary caregivers and family members, and/or between the family and formal care providers. Family disagreements around caregiving can give rise to conflicts or may rekindle longstanding and unresolved issues unrelated to the immediate situation (Levin & Murray, 2005). For instance, a husband, who spends increasingly more time at the home of his elderly mother, may find his spouse is critical that he is neglecting his own family. An adult daughter, living in New York, may fly to the family home monthly to help her sister care for their parents, who live next door. When sister #1 offers a care suggestion, she is met by an outburst from sister #2, who exclaims, "You are never here. You don't understand caring for a parent. You have always cared more for your own lifestyle than for our family." Clearly, in both situations there are family as well as care issues involved.

Research

Investigators have examined family conflicts around caregiving. Davis (1997) interviewed 40 caregivers of persons with Alzheimer's disease. These spouses, adult children, and other relatives had scored high on a pencil-and-paper measure of family conflicts around caregiving. Respondents described care situations around differences of opinion among family members about the cognitive limitations of the impaired kin, as well as family members' unwillingness to assist with care. Caregivers often described kin who were reluctant/unwilling to help with care as family members who had *always* been difficult. Davis speculated that the stresses of caregiving caused unresolved, latent intra-familial differences to surface again. Lyons et al. (2002) explored congruence between 63 elder care recipients and their family caregivers on the difficulties of care (e.g., family tensions, economic challenges, and assistance needs) and caregiving role strain. Although there was general agreement on the care recipient's *needs*, there was considerable disagreement in their perspectives of the *difficulties* of care. In an early paper describing Alzheimer's caregiving family functioning, Semple (1992) noted that differences in family members' attitudes and behaviors *toward the care recipient* were more likely to generate anger and resentment among family members, whereas differences in family attitudes and actions *toward the primary caregiver* were more likely to increase negative affect and depressive symptoms of the primary caregiver. Ward-Griffin & McKeever (2000) noted frequent conflicts between caregiving families of frail elders and community health nurses, and attributed those to the uncertain and shifting boundaries of care responsibilities. Based on a series of repeated interviews with women caregivers, Neufeld et al. (2008) concluded informal caregivers often feel as though their care observations and concerns are ignored, minimized, and/or discounted by professional providers. Taken together, such findings indicate the need for practice strategies that respond to elder care situations in ways that will strengthen families' capacity to address the needs of elder kin, as well as enhance communication with health professionals around meeting those needs. Although obvious, today's care environment often overlooks these nonessential but enrichment-oriented care approaches.

Family Caregiving Assistance

Studies of better ways to help and support family caregivers with home care are increasingly common in the family literature. Multicomponent caregiver interventions, combinations of aging and chronic disease education, caregiver and family counseling, support and respite services are designed to enhance caregiver and family coping (Davis et al., 2004). Most caregiver skill training studies have focused on individual caregivers (c.f. Davis et al., 2006; Gerdner et al., 2002; Grant et al., 2002; Ostwald et al., 1999), and the benefits of individual caregiver skill training have been documented (Sorensen et al., 2002). Fewer studies have focused on caregiving families, but two are remarkable for their longevity. Both focus on caregiving for individuals with Alzheimer's disease.

Over a 12-year period, Mittelman and colleagues' caregiver skill building programs at New York University involved 406 Alzheimer's disease caregiving families. Interventions were tailored according to the needs of primary caregivers and their families around: family communication skills, primary caregiver support, family conflict management, and dementia home-care skills (Mittelman et al., 1993; Mittelman et al., 1995). Because of the continuous deterioration expected in Alzheimer's disease, the elder's improvement was not studied. However, the investigators concluded that education, support, and respite interventions were beneficial for caregivers and caregiving families (Mittelman et al., 2004).

Findings from the REACH program were remarkably similar. REACH (*Resources to Enhance Alzheimer's Caregiver Health*) was jointly funded by the National Institutes of Aging and Nursing Research in 1995 to test a spectrum of caregiver interventions with socially, geographically, and ethnically diverse caregiving families (Hispanic and African Americans were sampled as well as Caucasian) at six sites around the United States. REACH interventions included caregiver education and support, group and family therapies, psycho-educational training for primary caregivers, home-based environmental adaptations, and telephone/computer-based caregiver counseling and support. Over 1,200 caregivers and their families received various combinations of these interventions, based on their needs. Although care recipient outcomes did not differ significantly by group or site, all six study sites reported that the treatment group caregivers had better outcomes (i.e., more positive, caregiver/family social, psychological, financial functioning, and environmental situations) than comparison group caregivers/families (Schulz et al., 2003). REACH investigators also concluded that multicomponent interventions are more effective than single-component interventions in helping informal caregivers and families, but they emphasized that combinations of interventions should be tailored according to specific caregiver/family needs (Schulz et al., 2003).

Under the aegis of the Cash and Counseling Program to offer Medicaid consumers choices on how to get help in the home (Knickman & Stone, 2007), the benefits of tailoring caregiver assistance have been demonstrated in states with large rural populations. In one demonstration project in Arkansas, 1,433 community-dwelling frail elders and their primary caregivers (93% family members) were randomized into either a traditional home-care agency services group or a caregiver-directed services group and followed for 10 months. While elder care recipients in both groups had comparable health and functional outcomes at the end of the 10-month period, caregivers who were allowed to select and direct service delivery used less assistance but reported emotional, physical, and economic well-being (Foster et al., 2005).

Finding Meaning in Family Care

Research findings over 2 decades indicate that the "failure to find meaning in caring" increases a family caregiver's sense of burden, distress, and role strain. Noonan and Tennstedt (1997) reported failure to "find meaning in caring" for

community-residing frail elders was correlated with higher levels of depressive symptoms and lower levels of self-esteem for 131 informal caregivers. Yates et al. (1999) reported that informal caregivers' perceptions of the quality of their relationship with the frail elder mediated the impact of caregiving stress and role overload on caregivers' depressive symptoms. From their intensive interviews with 16 family caregivers of elders, Caron and Bowers (2003) concluded that family members care for elders for both *interrelational* reasons (to maintain their relationship with the elder) as well as for *pragmatic* reasons (to provide safe, economic, high-quality care to the elder). These investigators speculated that if caregivers lose a sense of interrelational meaning from caregiving, they may find it easier to detach from the care recipient and discontinue care. From their extensive work with caregivers of frail elders, Archbold et al. (1992) observed that family caregivers need a strong interpersonal bond with the care recipient (mutuality) as well as a sense of caregiving competence (preparedness) to offset caregiving role strains. These and similar studies (Aneshensel et al., 1993; Chappell & Reid, 2002; Gold et al., 1995; Schulz & Beach, 1999) highlight the importance of finding meaning in care as a means of mediating family caregiving challenges, and point to this as yet another important area for practice improvement.

In summary, building an effective working relationship with caregivers and caregiving families requires an initial and ongoing assessment of the situation with respect to the individual needs of the specific needs of the caregiver and caregiving family as well as the elder. Studies suggest the "high-risk" family caregiving situation in a rural community will involve a family that lives at a distance from the care recipient; is challenged by the tasks and personal life demands of caregiving; and, experiences family conflicts around caregiving.

Future Directions

Implications for Family Practice

Elder care can be challenging for rural health-care providers who must develop effective ways of working with a network of family providers. The following three strategies can be helpful for working with families around rural caregiving.

Engage the family as a caregiving unit. Ideally, family caregiving planning should occur in the home of the elder, where family caregivers will be expected to communicate and collaborate in care. If possible and practical, the elder should be present and participate in family care planning meetings. Family norms of solidarity often can make it difficult for individuals to verbalize their views, particularly if they believe they are not shared by the group. Because lack of agreement among family members about the meaning and purpose of caregiving can make family care more difficult, it is important to provide the opportunity for each member to talk about their caregiving concerns. The next step is to develop a shared agreement about the

elder's current and likely future care needs. This can be difficult because it requires decision-making around emotionally charged issues, such as the elder's current self-care abilities and increasing needs for aid. Observe the dynamics of family interactions in care discussions (e.g., who speaks first, who takes charge in group discussion, who offers suggestions and who does not). This can offer insight into how families have made past decisions, and in this time of situational stress and family caregiving role ambiguity, can be expected to make current and future decisions.

Develop dynamic family caregiving plans. Determine who will function as primary, secondary, and auxiliary family caregivers, for example, who will give direct care, deal with financial matters, and negotiate for formal assistance. Help the family formulate a list of care needs tasks, including the time, effort, and costs of completing them. Encourage distance caregiver roles for family members who do not live in the community by engaging them in care that can be done at a distance, such as provision of emotional support, assistance with financial resources, and periodic services. If distance caregivers are expected to provide respite for in-home or community caregivers, these expectations should be formalized. Be prepared to revisit these plans and decisions as elder needs, family caregiver time, and availability change over time. Schedule periodic follow-up family meetings in the home if possible; if not, schedule telephone meetings.

Normalize family caregiving conflicts. Anticipate occasional family conflicts and frame them as ways to improve care delivery. Mentioning the challenges other families often identify around caregiving (e.g., limited time, uncertainty about who will do care, where to get information and aid, maintaining personal commitments in the midst of caregiving). Then encourage family members to verbalize their own feelings and concerns. To do this, it can be helpful to ask family members to describe what they would like to change in the care situation and the problems they see for themselves and others as caregivers.

Implications for Research

This chapter drew heavily on research findings aimed at caring for elders with cognitive disorders and, as such, did not attempt to evaluate the impact of the tested interventions on outcomes for the elder. Research is needed that will extend the testing of such interventions to situations in which the elder's (or other aged person in need of care) physical/mental outcomes or other illness features and outcomes of care can be evaluated.

The amount and timing of practice-based interventions has not been well evaluated either. In all likelihood, there are critical times for specific interventions that can reduce cost and improve outcomes for both the patient and family caregivers. Such explorations would best be initiated by clinicians/scientists and teams of health services researchers. Changing family demographics increases the likelihood that elder care in rural communities will be provided by health professionals who must work within the context of a network of family members – some who live close by and

some at a distance, as well as fictive kin with strong social ties and closer geographic proximity to the elder. In such situations there is little research on what constitutes the most effective composition, collaboration, and scope of family care in rural as well as urban and suburban communities.

As indicated in the literature, finding meaning in care can mediate caregiving challenges. This is yet another important area for future family caregiving studies. While the research foundation cited in this chapter addresses care of elders, the majority of theories addressing informal caregiving are grounded in stress, appraisal, and coping models. Comparatively few *family* theories focus on elder care; however, there is a promising body of literature addressing family care for children, particularly children with chronic illness from which we may learn. The work of Knafl and Deatrick has illuminated how the management style of parents around caring for a chronically ill child within the context of family life can be classified as either *thriving*, *accommodative*, *enduring*, *struggling*, or *floundering* (1986). Perhaps exploration of the meaning of elder care for families, particularly in rural communities where resources and assistance are scarce, may illuminate how some families with a frail and dependent elder find sufficient meaning in care to accommodate, or even thrive as family caregivers.

Implications for Education/Training

For those educated in urban centers, the question of whether their practice is appropriate for rural environments is seldom addressed. Further, there is little evidence to suggest that health professions education is adequately preparing graduates to address the complex issues embedded in the family, particularly issues that will require the coordination and cooperation of family members in caring for children and the disabled as well as elders. While many health professions students temporarily work in rural settings after graduation to fulfill educational funding support requirements, few are adequately prepared to understand the challenges and problems of community-based care of families in these sparsely populated areas. Even fewer are sufficiently invested in solving those problems to remain in a rural community after the conditions of their educational loan/grant is satisfied. To enhance students' interests and abilities for working with caregiving families in rural communities, family and rural health-care content should be standard in curricula and rural clinical education experiences should be part of every health profession student's educational clinical rotations.

Implications for Policy

In that families provide a significant amount of home care, effective programs of family assistance and support remain ongoing concerns for policy makers. The 2000 National Family Caregiver Support Program (NFCSP) was funded as part of the

Older Americans Act (HHS, 2003) to provide funds for state and local Area Agencies on Aging to provide family caregivers with counseling, training, support groups, respite care, and, information on available assistance programs. As of 2004, there were 56 State Units and 655 Area Agencies on Aging around the country (Administration on Aging, 2004). However, 2003 congressional appropriations for the NFCSP to states of \$155 million fell far short of the \$257 billion in un-reimbursed services that family caregivers provide (HHS, 2003). Some states are experimenting with caregiver reimbursement programs. For example, as part of the caregiver assistance demonstration project in Arkansas (2005), family caregivers had the option of paying themselves as well as others for providing selected care services. Project findings indicated family caregivers used these funds effectively for a combination of service purchases and self-reimbursement.

For rural communities, family caregiving is a common concern. With proportionally more individuals living alone, more community stakeholders need to be involved in grassroots care networks, programs, and policies. The smaller size and geographic separation of many families and the inclusion of more women in the workforce, justifies future exploration of community care *partnership* systems, where family and community members work together in building networks of care.

Finally, although limited, there are resources for elder caregiving assistance in the home. Another relatively unexplored rural health-care policy issue is the transition from home to long-term care for elders in communities that lack the growing array of long-term care opportunities found in urban population centers, such as assisted living facilities, progressive care communities and nursing homes. In these situations, rural *home-care providers and families who live at a distance but who are unable to provide elder care have few viable care alternatives. Federal, regional, and statewide programs of assistance are needed in rural communities, where families are not available to provide elder care and supportive services for elders who are too frail to continue to live at home.

Summary

Families are bound together by strong social norms and kinship ties that predicate caring for a frail and dependent member. Elder care in rural communities requires family members, many of whom live at a distance and are immersed in competing social and nuclear family responsibilities, to collaborate around care for a family member in the final years of life. The demands of elder care involves dispensing with familiar social and familial roles, and taking on complex tasks and unexpected responsibilities. Families are influenced by the experience of caregiving and family norms for solidarity and reciprocity can be challenged by elder care, unless the family develops a shared meaning of the value of elder care as part of family life. The high incidence of chronic illness, the progressive loss of functional independence and the increasing need for assistance make elder care an exemplar of challenging family caregiving. Given the significant contributions families make to

health care in the United States, rural clinicians, investigators, and policy makers must recognize informal care as a family issue and develop more effective ways of supporting families as the primary caregivers in rural communities.

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