Caregiving: Research · Practice · Policy
Series Editor: Ronda C. Talley
An Official Publication of The Rosalynn Carter Institute for Caregiving

Ronda C. Talley
Kathleen Chwalisz
Kathleen C. Buckwalter *Editors*

Rural Caregiving in the United States

Research • Practice • Policy

Series Foreword by
Former First Lady Rosalynn Carter

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Rural Caregiving in the United States

Research, Practice, Policy

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This book is dedicated to the memory of Mary Starke Harper, one of the nation's leading advocates for improving health care for rural caregivers, minorities, the elderly, and the mentally ill.

Foreword

From its inception in 1987, the Rosalynn Carter Institute for Caregiving (RCI) has sought to bring attention to the extraordinary contributions made by caregivers to their loved ones. I grew up in a home that was regularly transformed into a caregiving household when members of my family became seriously ill, disabled or frail with age, so my interest in the issue is personal. In my hometown of Plains, Georgia, as in most rural communities across our country, it was expected that family members and neighbors would take on the responsibility of providing care whenever illness struck close to home. Delivering such care with the love, respect and attention it deserves is both labor-intensive and personally demanding. Those who do so represent one of this nation's most significant yet underappreciated assets in our health delivery system.

When the RCI began, "caregiving" was found nowhere in the nation's health lexicon. Its existence was not a secret but rather simply accepted as a fact of life. In deciding on the direction and priorities of the new institute, we convened groups of family and professional caregivers from around the region to tell their personal stories. As I listened to neighbors describe caring for aged and/or chronically ill or disabled family members, I recognized that their experiences reflected mine. They testified that while caregiving for them was full of personal meaning and significance and could be extremely rewarding, it could also be fraught with anxiety, stress, and feelings of isolation. Many felt unprepared and most were overwhelmed at times. A critical issue in the "field" of caregiving, I realized, was the need to better understand the kinds of policies and programs necessary to support those who quietly and consistently care for loved ones.

With the aging of America's Baby Boomers expecting to double the elderly population in the next 20 years, deinstitutionalization of individuals with chronic mental illnesses and developmental disabilities, a rising percentage of women in the workforce, smaller and more dispersed families, changes in the role of hospitals, and a range of other factors, caregiving has become one of the most significant issues of our time. Caregiving as an area of research, as a focus and concern of policy making, and as an area of professional training and practice has reached a new and unparalleled level of importance in our society and indeed globally.

As we survey the field of caregiving today, we recognize that it is an essential component of long-term care in the community, yet also a potential health risk for those who provide care. The basic features of a public health approach have emerged: a focus on populations of caregivers and recipients, tracking and surveillance of health risks, understanding the factors associated with risk status, and the development and testing of the effectiveness of various interventions to maximize benefits for both the recipients of care and their providers.

The accumulated wisdom from this work is represented in the volumes that make up the Springer Caregiving Series. This series presents a broad portrait of the nature of caregiving in the United States in the twenty-first century. Most Americans have been, are now, or will be caregivers. With our society's increasing demands for care, we cannot expect a high quality of life for our seniors and others living with limitations due to illness or disability unless we understand and support the work of caregivers. Without thoughtful planning, intelligent policies, and sensitive interventions there is the risk that the work of family, paraprofessional, and professional caregivers will become intolerably difficult and burdensome. We cannot let this happen.

Readers of this series will find hope and evidence that improved support for family and professional caregivers lies within our reach. The field of caregiving has matured and, as evidenced in these volumes, has generated rigorous and practical research findings to guide effective and enlightened policy and program options. My hope is that these volumes will play an important role in documenting the research base, guiding practice, and moving our nation toward effective polices to support all of America's caregivers.

Rosalynn Carter

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Mary Starke Harper, Ph.D., RN, FAAN deceased in 2006 at age 86. Dr. Harper began her 65-year medical career as a nurse in Alabama, to whom this book is dedicated, caring for an aging George Washington Carver. She became one of the nation's leading advocates for improving health care for minorities, the elderly, and the mentally ill. Dr. Harper spent many years as a nurse in veteran's hospitals, then became a policymaker with the National Institutes of Health and an adviser to four presidents. She also helped begin an NIH program that has trained thousands of minority scientists and health-care workers. Dr. Harper was the last surviving participant in the notorious Tuskegee syphilis project, a U.S. Public Health Service study in which black men in Macon County, AL, were deliberately left untreated to determine the long-term effects of the often fatal venereal disease. Years later, after a conscience-stricken Dr. Harper understood her unwitting role in the project, she vowed to change the way the government conducted studies on people. She William Jefferson served on White House advisory panels for every president from Jimmy Carter to Clinton. She was on the board of directors of the National Mental Health Association and consulted with NIH, Johnson & Johnson, and the Rosalynn Carter Institute for Caregiving.

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Chapter 1
Caregiving in Rural America: A Matter of Culture

Kathleen Chwalisz, Kathleen C. Buckwalter, and Ronda C. Talley*

Family caregiving is a universal experience, an act of love and filial responsibility, but also an essential part of the health and long-term care systems. In 2004, an estimated 44.4 million Americans over the age of 18 years (21% of the U.S. adult population) provided unpaid care for another adult in an estimated 22.9 million households (National Alliance for Caregiving and AARP, 2004). Family or other informal caregiving, although unpaid, has been estimated to have a value to American society of $257 billion annually (Arno, 2002), at a substantial cost to the individuals providing the care.

Nature of Caregivers and Care Recipients

Definitions

To define *caregiving*, we turned to several well-known caregiving researchers and advocacy groups. The National Family Caregivers Association (NFCA) (2002) defines caregiving as the necessary physical and mental health support to care for a family member. One description of informal or family caregiving that has been widely accepted over time was offered in 1985 by Horowitz, who indicated that informal care involves four dimensions: *direct care* (helping to dress, managing

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*The findings and conclusions in this chapter are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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medications); *emotional care* (providing social support and encouragement); *mediation care* (negotiating with others on behalf of the care receiver); and *financial care* (through managing fiscal resources, including gifts or service purchases). The challenges of actually providing informal or family 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).

Relatedly, the Administration on Aging (2006) defines a *caregive*r as "anyone who provides assistance to another in need." The National Alliance for Caregiving (NAC) and AARP (2004) define caregiving as caring for an adult family member or friend. However, most definitions of caregiving adopt a life-span perspective that includes children and youth as both caregivers and care recipients.

More specifically, *family caregiver* is defined by the Health Plan of New York and NAC (2005) as a person who cares for relatives and loved ones. MetLife and National Alliance for Caregiving (2006) expanded on this definition by specifying additional qualifiers, stating that a family caregiver is "a person who cares for relatives and loved ones who are frail, elderly, or who have a physical or mental disability." Similarly, the NFCA (2002) added that family caregivers provide a vast array of emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis. The NFCA advocates for the term *family caregiver* to be defined broadly and to include friends and neighbors who assist with care by providing respite, running errands, or doing a range of other tasks that support the caregiver and care recipient. In this volume, we will use the terms *informal caregiver* and *family caregiver* interchangeably and employ the comprehensive NFCA definition of *family caregiver* to refer to caring relatives, friends, and neighbors of all ages across the life span (see *Intergenerational Caregiving*, this series).

Throughout the volume, we use the term *professional caregivers* to refer to paid care providers such as physicians, nurses, social workers, psychologists, case managers, hospice workers, home health aides, and many others. The designation as professional caregiver excludes family caregivers who may receive funds to provide care from new and emerging sources, such as the Medicaid Cash and Counseling Demonstration Program.

Characteristics

A 2004 survey conducted by the NAC and AARP provided perhaps the most comprehensive current picture of caregiving for adults in the United States. In the national survey of 6,139 adults, 1,247 caregivers were identified and surveyed to gather information about their characteristics and activities. The majority of caregivers were women (61%), and women provided more hours of care and higher levels of care than male caregivers. Women were also more likely to report feeling like they did not have a choice in taking on the caregiving role.

Seventy-nine percent of care recipients were 50 years of age or older, with an average age of 75 years, and had caregivers who were most likely to be adult children or grandchildren (National Alliance for Caregiving and AARP, 2004). Older care recipients typically received care for issues related to aging or physical illness (e.g., diabetes, cancer, heart disease). In contrast, younger care recipients had an average age of 33 years and had caregivers who were parents, siblings, or nonrelatives; they typically received care because of mental illness or mental retardation.

More than half (55%) of care recipients in the National Alliance for Caregiving and AARP (2004) who did not live with their caregiver lived in their own home; 24% lived with the caregiver, and about 12% of care recipients lived in formal facilities (e.g., nursing home, assisted living, retirement community, psychiatric facilities, group homes). The majority of care recipients who did not live with the caregiver lived within 20 min of the caregiver (42%) and another 19% lived within an hour's travel time of their caregivers. Thus, only 15% of caregivers were providing assistance long-distance.

Twenty-seven percent of caregivers lived in rural areas (National Alliance for Caregiving and AARP, 2004). Rural caregivers, like other rural Americans, possess unique characteristics and needs. To date, however, relatively little has been done to understand rural caregiving specifically and to address the needs of rural caregivers. Much of the program development and research related to rural caregiving has involved the application of models developed in urban populations to rural caregiving situations. In this volume, experts on rural caregiving raise issues unique to rural caregiving situations, present what is known about caregiving in rural contexts, and identify future directions for rural caregiving practice, research, education and training, and policy and advocacy.

Activities

Nearly half of all caregivers (48%) in the National Alliance for Caregiving and AARP (2004) provided 8 h or less of care per week, but 17% provided 40 h or more. Caregivers may provide assistance with instrumental activities of daily living (IADLs), e.g., transportation, shopping, housework, arranging services, managing finances, preparing meals; and/or activities of daily living (ADLs), e.g., dressing, bathing, toileting, feeding, mobility. The most frequent IADL assistance reported in the NAC/AARP study was in the areas of transportation (82%) and grocery shopping (75%), followed by housework (69%), managing finances (64%), preparing meals (59%), helping with medication (41%), and managing services (30%). A higher proportion of African American and Hispanic caregivers reported assisting with medications than did White or Asian American caregivers. Half of all caregivers surveyed by NAC and AARP reported assisting with ADLs. Caregivers who provided ADL assistance were more likely to (a) provide more than 8 h of help per week, (b) care for individuals with Alzheimer's disease or dementia, (c) live with the care recipient, and (d) have a care recipient who was 50 years of age or older. One quarter of caregivers provided assistance with three or more ADLs; the most frequently reported ADL assistance was help with getting in and out of beds and chairs (36% of caregivers reported), dressing (29%), and bathing (26%). These data confirm that caregivers provide a great deal of assistance in a wide variety of areas. No breakdown was provided as to whether rural and urban caregivers differ.

In compiling a series of principles for change in public policy, a collaborative group of family caregiving advocacy organizations noted critical caregiver needs that are currently not being met (*Family Caregiving and Public Policy: Principles for Change* 2003). Among other things, family caregivers need ongoing education and training to meet the complex responsibilities of the role. Affordable, readily available, comprehensive, quality, and coordinated services – particularly respite services – need to be available across all care settings. Family-friendly policies in the workplace are also needed (e.g., flextime, work-at-home, job sharing, dependent care accounts). The policy group also underscored the need for health-care policy that incorporates family caregivers as a crucial component of the health-care system and the need for a qualified, affordable, and sustainable health-care workforce across all settings.

Outcomes

Caregiving is a long-term commitment, typically lasting for 8 years or more, and caregivers tend to underestimate the length and magnitude of their obligation (MetLife, 1999). Approximately two thirds of American caregivers are also employed, with average individual financial losses of $659,139 over their lifetimes, as well as work-related losses such as compromised opportunities and promotions (MetLife, 1999). The psychological and physical toll of caregiving has been well documented. Studies indicate that informal caregivers experience more role strain, depression, and physical health problems than age-matched non-caregivers, as well as more marital discord, family dysfunction, social isolation, and loneliness (Aneshensel et al., 1993; Johnson, 1998; Vedhara et al., 2000). A meta-analysis of 23 studies of caregiver health over a 38-year period revealed that caregivers report poorer overall health, greater use of medications, a 23% higher level of stress hormones, and a 15% lower level of antibody response (Vitaliano et al., 2004). In the National Alliance for Caregiving and AARP (2004) survey, the two greatest predictors of physical strain were reported to be health status and whether the caregiver felt like he or she had a choice in taking on the role. They reported the two greatest predictors of caregiver emotional stress were their level of burden (i.e., amount and complexity of caregiving responsibilities) and whether the caregiver felt he or she had a choice in the matter. Negative caregiver outcomes are compounded by loss of social support and limited knowledge of local resources (Magilvy & Congdon, 2000). Strain is a major precipitant of premature and inappropriate institutionalization of rural elders; especially among caregivers who perceive they have no alternative care options (Congdon & Magilvy, 1998). As caregivers break down from the strain of caregiving, health-care costs are predicted to skyrocket with the loss of the unpaid care provided by family caregivers and the additional costs associated with provision of physical and mental health care to those who are affected (Chwalisz & Hanson, 2001).

What Does It Mean to Be Rural?

The first step in addressing the issues and needs of rural caregivers is the comprehensive consideration of what it means to be rural. Multiple perspectives on rurality are necessary to yield a complete picture of rural America and the issues of rural people. Rural communities are not merely smaller versions of urban communities, and the issues of rural people may not be extrapolated from knowledge of urban issues and people.

Quantitative Definitions of Rural

When one first thinks about defining what rural is, census definitions come to mind. The United States Office of Management and Budget (OMB), in conjunction with the 2000 Census, developed a new "core-based statistical area" approach to defining rural and urban areas (U.S. Department of Agriculture and Economic Research Service, 2003). In this system, *metropolitan* areas are central counties with urbanized areas of 50,000 or more residents. Surrounding counties are also classified as metropolitan if 25% or more of their residents commute to the core metropolitan area. Non-metropolitan areas are divided into two types. Counties with urban clusters that have populations between 10,000 and 50,000 are considered to be *micropolitan* areas, and surrounding counties with a minimum of 25% commuting to the micropolitan core area are also considered micropolitan. *Noncore* areas are all counties not meeting the micropolitan classification criteria. Noncore counties with towns of less than 10,000 population have also been referred to as *town counties* (Henderson & Weiler, 2004). One might take these rural/urban distinctions even further by reintroducing to the conceptualization OMB's 1993 notion of a rural area as one with population clusters smaller than 2,500 residents; frontier areas can be further identified by including even lower population densities.

The updated core-based approach to classifying the U.S. population makes it easier for individuals, researchers, and policy makers to attend to the different experiences of residents of these different areas. For example, a resident of a micropolitan area may have experiences of seeking health services that are more similar, in some respects, to an urban resident (e.g., distance traveled to see a family physician), but more similar in other respects (e.g., distance traveled to see a cardiologist) to a noncore or rural resident. Ricketts (2004) criticized previous research involving rural–urban comparisons for aggregating widely divergent non-metropolitan populations. Efforts to understand the needs of rural persons and develop rural programs must always take into account the specific nature of the particular region.

Economic and Social Realities of Rural Areas

Rural areas account for 59 million people, while 55 million people live in non-metropolitan areas (U.S. Census Bureau, 2000). Of the rural population, 26 million live in metropolitan areas and almost half of the non-metropolitan population, or 23 million, were actually urban dwellers. The rural, non-metropolitan population in 2000 was 33 million (U.S. Census Bureau) and covered 80% of the nation's land (Whitener & McGranahan, 2003).

Rural America is a complex mix of racial and ethnic groups, terrains, climates, businesses, natural amenities, and institutions. Whereas farming dominated the rural economy through the mid-twentieth century, the majority of rural counties now have economic systems involving manufacturing, services, natural resources, and recreation. Rural jobs are increasingly focused in consumer services (e.g., retail, education, health care) for local residents (Whitener & McGranahan, 2003). Rural areas vary widely in terms of prosperity indicators of population growth, education, unemployment, and overall socioeconomic status of their residents. For example, rural poverty levels in general are at their lowest since 1980, but rural areas in the South have significantly higher poverty rates and lower income than the general population (U.S. Department of Agriculture and Economic Research Service, 2005). One third of the nation's poor live in rural areas, and the stress of living in poverty in rural areas, combined with social isolation and a lack of social agencies and mainstream institutions, has been implicated in poorer physical and mental health outcomes (Fox et al., 2001).

Various economic changes have led to a decreasing sense of community in rural areas. Out-migration of younger and better skilled individuals may leave rural areas vulnerable because of a decreasing population and a shrinking tax base. This may result in fewer services in areas with higher dependency needs – that is, those areas having a population with higher proportions of residents older than 65 years or younger than 18 years of age (Blank et al., 1995). Rural youth may experience deteriorating schools with a lack of services for special needs. Older adults, especially those with fixed incomes, may become *increasingly* isolated as the availability of goods and services *decreases* with diminishing community resources (Hargrove & Breazeale, 1993). An *increasing* number of urban workers are living in rural areas but spending a great deal of time outside of their home communities, resulting in weaker community ties and less economic development in these rural "bedroom" communities (Blank et al., 1995).

Rural Culture

Hargrove (2000) suggested that differences between rural and urban individuals are not innate but rather a reflection of the environments in which people live and work. Various environmental and psychological features of rural areas (e.g., topography, ethnic and racial composition, values, self-perceptions, lifestyle) have not been sufficiently incorporated into our definition of rural (Blank et al., 1995). Logan (2000) noted that Americans typically attribute to rural areas the characteristics that we as a society fear have been lost in our city or suburban way of life, such as hard work, family, community, nature, peace, and safety. On the other hand, research on rural values done in the 1970s and 1980s painted a picture of rural residents as "relatively more conservative, religious, puritanical, ascetic, ethnocentric, isolationist, intolerant of heterodox ideas and values, prejudiced, uninformed, authoritarian, and family centered than nonrural residents" (McLeskey et al., 1988, p. 177). Based on in-depth telephone interviews with a stratified random sample of 242 rural, urban, and suburban individuals, a conflicting picture of rural America emerged "centered on a series of dichotomies – rural life represents traditional American values, but is behind the times; rural life is more relaxed and slower than city life, but harder and more grueling; rural life is friendly, but intolerant of outsiders and difference; and rural life is richer in *community* life, but epitomized by *individuals* struggling independently to make ends meet" (W. K. Kellogg Foundation, 2002, p. 1). These conflicting views of rurality may reflect rapidly changing social and economic conditions in rural areas and the diversity (e.g., regional, ethnic, religious) that exists among rural people.

Although a bit dated, Fitchen's (1991) massive qualitative field study of rural New York yielded one of the best and most comprehensive discussions of rural changes and rural culture, anticipating both the issues and the nature of rural America today. Fitchen began by discussing the farm crisis of the 1980s and its implications for families and communities. In her research, she described the changing rural economy, changing demographics in rural areas, environmental and land use problems, and changes in community services and local government that bring us to the status of rural America today. In the wake of so many changes, the dominant theme among participants in Fitchen's study was identity. The images of rural life as isolated, small-town, and agrarian no longer held. The ideas of rural as antiurban, rural as small and cohesive communities, or rural as a unique lifestyle uninfluenced by mass society no longer fit.

The residents of rural areas appear to cling to agriculture, or at least to the natural surroundings, as a basis for identity (Fitchen, 1991). The land is where social relationships are grounded and certain socioculturally important events take place (i.e., father taking son on his first hunting trip). The land separates the rural life from the city life. Other components of the rural identity include a high quality of life, making sacrifices or living with less (i.e., nonmaterial life), and a slower speed of life. Rural communities are considered by their members to be unique, often defined by contrasts with other communities, and characterized by friendliness and members all knowing one another – but economic and demographic changes in rural communities are eroding people's sense of knowing one another. Some participants in Fitchen's study talked about a "modern rural" identity which appears to reflect more of a suburban mentality.

The Rural Health-Care System

Rural residents exhibit health disparities when compared with urban and suburban residents. The Center for Disease Control and Prevention's 2001 urban and rural health chartbook revealed that rural residents smoke more, exercise less, have poorer diets, and are more likely to be obese (National Center for Health Statistics, 2001). Specific regional disparities can also be identified within the chartbook findings. For example, rural residents in the South had higher rates of poverty, adult smoking, deaths related to heart disease, and births to adolescents (Hartley, 2004). Impoverished rural areas are associated with such factors as inadequate housing, poor nutrition, exposure to environmental toxins, and limited access to and underutilization of health-care services (National Center for Health Statistics, 2001).

The National Rural Health Association (2007) noted that rural residents are less likely to have employer-provided health-care coverage, are nearly twice as likely to die from unintentional injuries, tend to be poorer, are more likely as youth to abuse alcohol and smokeless tobacco, have a higher suicide rate, have less access to health care and mental health services, and have greater transportation difficulties in reaching health-care providers. Of particular concern is the fact that health-care services in rural areas are less accessible, less specialized, and more costly to deliver than in urban areas (Rogers, 1993). McAuley et al. (2004) noted significant rural–urban differences in the use of home care, likely because of Medicaid coverage. Home care may substitute for less available forms of care in rural areas, so it is essential that policies continue to support this important care option. Rural health-care facilities are few and far between. Hospitals may be old and have limited technology available (Hood, 2004), prompting the need for transfers to urban hospitals and additional risks for transferred patients (Mantone, 2005). Availability of pharmacies may also be limited in rural, particularly non-White neighborhoods (Alliance for Health Reform, 2004). Despite federal and state policies that have encouraged community-based and in-home services as economically sound alternatives to institutional care, rural care recipients have a narrower range of care options and fewer community-based alternatives available to them. Thus, higher utilization rates of nursing home services continue in rural settings (Coward et al., 1996).

Shortage of Health-Care Professionals

The limited number of health-care professionals is also a major problem facing rural health settings. Approximately 11% of primary care physicians practice in rural health settings across the United States (Brooks et al., 2002). The number of primary care physicians of color in rural areas is even lower (National Center for Health Statistics, 2004). Specialist shortages include pharmacists, psychiatrists, psychologists, and social workers; registered nurses account for the bulk of health-care professionals in rural areas (Wakefield, 2005). The shortage of health-care professionals in rural areas leads to a tremendous discrepancy in supply and demand for services, which forces many rural health-care professionals to engage in a sort of "patchwork" provision of services, making the best out of available resources and their knowledge and skills to address the complex needs of patients.

Discrepancies in Policy

Rural health-care systems have often fallen through the cracks in existing policies related to the improvement of service quality (Institute of Medicine, 2005), methods of financing (Wakefield, 2005), and the acquisition of assistance to improve the health conditions of patients (IOM). These problems are largely attributable to general efforts to address problems in rural settings based on urban models and initiatives, with the assumption being that urban models will also apply to rural settings and will lead to similar outcomes (Wakefield). However, even the most basic of urban policy-based initiatives may not be relevant to rural areas. For example, the Centers for Medicare and Medicaid Services (CMS) contracted various quality improvement organizations (QIOs) to address such areas as quality improvement, education, and the resolution of complaints for beneficiaries. At the same time, CMS used an incentive program that included urban-based evaluation criteria, such as the need to reach large populations and/or improve statewide averages on various quality indicators. Thus, QIOs had no incentive to address the needs of the rural health-care system (IOM). To affect the rural health-care system, policy makers must develop rural models, based on rural culture, economics, and community.

Rural Caregivers

Caregiver needs and challenges in rural communities include program availability and acceptability, inadequate mental health services, and changing needs over time. Additionally, caregiver attitudes, values and beliefs, stigma, and reluctance to seek help and to spend money on services impede the development and provision of programs designed to assist them. A focus group and interview study of rural caregivers of persons with dementia revealed that living in rural areas can be associated with various positive effects for caregivers, such as the familiarity of a small community with members being supportive and tolerant of care recipient changes, willingness to "look out for" one another, knowledge of available services, and good access to one another for support (O'Reilly & Strong, 1997). On the other hand, these investigators also found negative effects of rural life such as a lack of privacy, lack of education and misunderstandings about dementia, and geographical distance between family members leading to difficulty accessing help from family and friends.

The majority of caregiving situations, and a higher proportion of caregiving situations in rural areas, involve caring for older adults. Many of the attitudes about and barriers to service provision for this group are generalizable to rural caregivers of persons in other age groups and with various mental and physical health conditions. Elder caregiving networks are characterized by their continuous evolution over time (Peek et al., 1997). Whereas most elders initially require only limited assistance with IADLs, such as meal preparation, shopping, and financial management, after reaching a certain level of frailty, the need for assistance increases dramatically to more personal care with ADLs, such as bathing, toileting, feeding, grooming, and transferring. In rural communities, the type of assistance needed may not be readily available or may require that a combination of caregivers and services be “cobbled” together to keep the care recipient in the home. Ideally, the rural service delivery system would be designed to reflect this knowledge: that the need for services will vary over time, and that care recipients and caregivers will transition between community-based informal support systems and levels of professional care or care settings.

Complicating matters further is the fact that service usage can vary across counties even within the same rural region, in part because of a lack of consistency in definitions and eligibility requirements for similar programs. All too often rural caregivers are lost to follow-up after initial screening as agencies that serve rural elders are unable to adequately track vital caregiver information over time. To more effectively meet the changing needs of caregivers of the rural elderly, data must be maintained, archived, and retrieved easily to maximize the information available to both the aging and health-care systems (Lemke et al., 2001).

Barriers to Service Provision

Barriers to effective support and services for rural caregivers can be broadly classified as structural or attitudinal in nature. Structural barriers adversely affect help-seeking behavior and the experience of being a caregiver. These barriers include (a) lack of coordination in the service delivery system; (b) cost of services; (c) overburdened, understaffed, or unavailable service agencies; (d) distance and transportation; (e) restrictive reimbursement policies; (f) lack of access to comprehensive diagnostic and assessment services; and (g) unwillingness of physicians to make referrals for services.

Additionally, the rural elderly are often provided with “scaled down urban service models that fail to meet their needs or are insensitive to the real differences between urban and rural areas” (Van Hook, 1987, p. 13). Rather than a thoughtless “imposition approach,” success will be more likely if services are integrated with other local programs and informal helping networks. Service providers must understand and be sensitive to the rural value system and social ecology of the area (Buckwalter et al., 1994).

Unfortunately, most rural communities are too limited in the fiscal resources and infrastructure (e.g., program planners, trained workers, transportation) needed to develop their own community-based programs (Lemke et al., 2001), resulting in barriers characterized as “the 7 A’s”: lack of *awareness*, *availability*, *access*, *affordability*, *adequacy*, *appropriateness*, and *acceptability* (Krout, 1994; Williams et al., 1991). Although not unique to caregivers of the rural elderly, these structural barriers surely affect them. Rural residents, especially older adults and their caregivers, may be *unaware* of services in their area, or the lack of specific service *availability* in the community may decrease service *affordability* and increase the time required to *access* those services. Locally available services may be fragmented or of lesser quality (*adequacy*) or may not articulate with urban referral centers. Further, services may not target the health-care needs (both health promotion/maintenance and chronic illness management) of older residents (*appropriateness*) or be *acceptable* to their cultural norms and ethnic beliefs. For example, caregivers of older persons with dementia reported "the need to travel long distances effectively eliminated the intended benefit of support services (e.g., respite/adult day care, support groups) because the free time caregivers gained was spent in the car" (Connell et al., 1996, p. 23). Buckwalter et al. (1994) investigated the needs, resources, and responses of 107 rural caregivers of older persons with Alzheimer's disease. Findings revealed that only 51% of caregivers used any community-based services. Costs averaged $73 per month, the majority of which were borne by the caregivers. These rural caregivers reported that cost was a major barrier to service use, and that they were "saving their money to buy care in a good nursing home." Other reasons given for low service use were concerns over confidentiality, a common problem in smaller communities where "everyone knows everybody's business"; poorly publicized programs; perception that services involved "too much red-tape"; and too many restrictions in programs, such as those that are means-tested (Connell et al., 1996).

The attitudes of caregivers of the rural elderly can also impede receipt of needed assistance. Attitudinal barriers include (a) stigma and guilt about seeking help and receiving services; (b) value of self-reliance; (c) belief that family members should be responsible for care; (d) reluctance to seek services until a crisis occurs; (e) denial of symptoms; and (f) ageism. For example, in the Buckwalter group's previously described survey, some caregivers refused to use services involving aid from an agency, because they felt this was "too close to charity" and that "people should be self-sufficient" and "take care of their own problems" (1994, p. 312). Similarly, Connell et al. (1996) noted that during focus group interviews, rural family caregivers expressed reluctance to seek community-based services they perceived as "hand-outs" or "welfare" (p. 23).

Rural elders and their caregivers who believe that they should be able to handle problems themselves may view any form of assistance, particularly help related to mental health, as a sign of personal weakness or failure (Smith et al., 1997). Denial of symptoms and reluctance to seek help can be attributed to feelings of shame, stigma, fear of institutionalization, and suspicion of the health-care and service systems (Collins et al., 1991). Together with concerns about costs and confidentiality, these values and beliefs, and especially the stigma associated with the use of mental health or counseling services, accounts in large part for the low use of formal services by caregivers of the rural elderly.

Despite these barriers, caregivers in the Buckwalter et al. (1994) survey were highly motivated to undertake a difficult and burdensome caregiving role, and many reported a deep sense of personal satisfaction and growth from the caregiving experience. A strong sense of moral obligation and personal desire were prime motivations for becoming a caregiver, and reflected cultural and religious values of the rural Midwest. For example, 92% of respondents indicated that "caring is the Christian thing to do" and a similar percentage reported that "God helps them in their caregiving efforts." These findings are supported by other research documenting that even across cultures (Mausbach et al., 2003), rural elders believed they had a responsibility to help themselves, and also felt that, along with God's help, they could survive life's challenges (Davis & Magilvy, 2000; Martinez, 1999).

Genesis of the Rosalynn Carter Institute Caregiving Books

Efforts to develop this volume began in 2000, when Johnson & Johnson, an international health-care business leader, and Dr. Ronda Talley, executive director of the Rosalynn Carter Institute for Caregiving, began discussions that led to the development of the Johnson & Johnson/Rosalynn Carter Institute Caregivers Program. Through this program, the Rosalynn Carter Institute convened a series of ten expert panels over a period of several years to address a wide variety of caregiving issues. These included disability; Alzheimer's disease; cancer; mental health; life-span caregiving; rural caregiving; intergenerational caregiving; education, training, and support programs for caregivers; interdisciplinary caregiving; and building community caregiving capacity. With Springer as our partner, the RCI books were integrated into the Springer caregiving book series, *Caregiving: Research*, *Policy*, *and Practice* with Dr. Talley as Editor-in-Chief. In 2010, we launched the first book in the series, *The Multiple Dimensions of Caregiving and Disability.* The second release in the series is this volume, *Rural Caregiving: Research*, *Practice*, *Education*, *and Policy Issues.*

Introduction to Rural Caregiving Book

The first section of this volume includes discussions of issues related to specific caregiving populations. Given that most caregiving occurs in the context of family relationships, this volume begins with the chapter "Family Caregiving: Implications for Rural Practice, Policy, Education, and Research" by Mary Harper, Catherine Gilliss, and Linda Davis. Next is Kathleen Buckwalter and Linda Davis's chapter, "Elder Caregiving in Rural Communities." Caregivers of older adults represent nearly 80% of caregivers, recognized by the health-care system, in the United States. At the other end of the life span are caregivers of children and youth, discussed in "Care for Children and Youth" by Susan Walker and Kathy Reschke. Although this caregiving population is typically not recognized by the health-care system, caregivers of children and youth are critical to the well-being of rural communities and face some of the same challenges as rural caregivers of persons with illnesses and injuries.

This volume was designed to include discussions of rural caregiving from a variety of perspectives: practice, research, education and training, and policy and advocacy. Beyond the application of these four areas to all topics, three chapters focus specifically on practice and research issues. Related to practice, experts have been enlisted to discuss issues of physical and mental health for rural caregivers. Physical health issues and particularly rural–urban and racial and ethnic health disparities are discussed by Tawanda Greer. Mental health concerns for caregivers in rural communities are discussed by Martin Morthland and Forrest Scogin. The unique issues of doing research in rural areas and on rural caregiving are discussed in a chapter by Turner Goins and Melinda Spencer.

Issues related to the rural health system and health-care delivery are addressed in two chapters. In "Workforce Issues in Rural Caregiving," Patricia Calico identifies the current health-care workforce shortages and recommends ways to address them. One particularly promising approach to addressing rural health-care limitations is the use of telemedicine, which is discussed by Peter Yellowlees, Thomas Nesbitt, and Stacey Cole in the chapter "Telemedicine: The Use of Information Technology to Support Rural Caregiving."

Finally, a number of specific strategies to assist rural caregivers are set forth. Specific needs related to education, training, and support for rural caregivers are discussed by Kathleen Chwalisz and colleagues Stephanie Clancy Dollinger, Erin Zerth, and Vivian Tamkin. Program development and delivery issues are elucidated by Carolyn Wilkin and Brianne McCarthy Stanback in their chapter, "Strategies to Support Rural Caregivers." State responsibilities to support rural caregivers are discussed by Maria Greene and colleagues Molly Perkins, Kathy Scott, and Cliff Burt. These authors illustrate state-related support for caregivers with examples of effective programs in Georgia.

Concluding Comments

It is impossible to address all aspects of rural caregiving in a single volume. This text is the first attempt to highlight, in one place, critical issues in rural caregiving, presenting both current status and future directions. We hope that this volume will stimulate further developments in practice, research, training, and policy that will improve life for rural caregivers and improve the well-being of all rural persons.

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Part I
Caregiving Populations

Chapter 2
Family Caregiving: Implications for Rural Practice, Policy, Education, and Research

Linda Lindsey Davis, Catherine Lynch Gilliss, and Mary Starke Harper

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 long-standing 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 (*R*esources to *E*nhance *A*lzheimer's *C*aregiver *H*ealth) 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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Chapter 3
Elder Caregiving in Rural Communities

Kathleen C. Buckwalter and Linda L. Davis

Caring for Elders in Rural Communities

Projected demographic trends indicate a dramatic increase in this country’s elderly population in the twenty-first century (Rogers, 2002; U.S. Census Bureau, 2000). Thus, elder care looms as both a current and future public health concern for our nation. Nowhere is this issue more pressing than in rural communities, which have proportionately more older residents (Rogers, 2002); 29 states, mostly in the Midwest and South, report elder populations in excess of the national average (12.4%), with almost one in three Black elders in the South residing in a rural area (Coward & Krout, 1998; U.S. Census, 2000). At present about a quarter of all elders in the United States live with either their spouses or alone in a rural community. Because of employment-related migration of young and middle-aged adults to urban centers, fewer elders live with or have regular access to their children and grandchildren, which can be a chronically stressful situation (Johnson, 1998). Rural America is characterized by growing diversity and the rural aged are a heterogeneous lot, who present unique challenges to the health, service, and aging networks.

Informal caregivers currently provide more than 70% of care services for community-dwelling elders, an estimated $45–94 billion worth of direct and indirect care services each year (Arno et al., 1999). As more “baby boomers” (persons born between 1946 and 1964) reach age 65, the need to inform and support family members, neighbors, and friends who provide the care that allows rural elders to remain in their homes will become an even more important societal issue. This chapter explores some of the many barriers encountered by and needs of caregivers of elders in rural communities, as well as offering potential solutions to these challenges. The R.U.R.A.L. (Relevance, Unity, Responsiveness, Access, and Local Leadership)

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Elder Caregiver Program Planning Model is set forth as a framework from which to develop effective elder caregiver assistance programs. Application of the model is illustrated by highlighting characteristics of a number of successful programs targeting caregivers of the rural elderly. Current and future practice, research, education and policy issues related to caring for elders in rural communities are then summarized. To set the context for this model, the chapter begins with a brief overview of key socio-demographic, health, and economic factors that impact elder caregiving in rural communities.

Rural Elders: Health Care, Socio-demographic, and Economic Considerations

Since the 1950s the rural population has been aging rapidly as a result of the desire of elders to “age-in-place,” the out-migration of youth, and the immigration of elders from urban areas (Siegel, 1993). The health care needs of this growing cohort present a particular challenge to both formal and informal caregivers. For example, rural elders may not seek or engage in routine health screening or health maintenance programs without caregiver encouragement, and care for chronic illness may not be sought unless or until there is a crisis.

Research refutes the commonly held stereotype of the “hale and hardy” rural elder (Coburn & Bolda, 2001), a myth Krout (1994) attributed to the misconception that because of healthy and physically robust lifestyles, rural elders and their caregivers have few health problems. Rather, the number of elderly persons at risk for disability, functional limitations, and chronic health problems continues to increase, thereby creating a greater need for medical services, mental health and social services, and more caregivers (Rogers, 2002). An estimated 87% of the rural aged experiences some sort of chronic illness (Johnson, 1991). Despite these high prevalence rates, one in three persons with a chronic health condition does not understand what services they are eligible to receive, how to use these services, or who provides them. There is thus a critical need for more consumer education and better information and referral services for older persons and their caregivers (Institute for Health & Aging, 1996). Chronic health issues that require long-term caregiving are a particular concern for the “oldest-old” segment of the population (those 85+ years), which increased by 37% from 1980 to 1990, compared to only a 16% increase in the 60–84-year-old cohort (Rogers, 1999).

The same economic and service-related issues that affect caregivers of persons throughout the life span also impact caregivers of the rural elderly. Of particular concern are accessibility issues: health-care services are less accessible, less specialized, and more costly to deliver than in urban areas (Rogers, 1993). A recent study (McAuley et al., 2004) noted that there are significant rural–urban differences in the use of home care, likely due to Medicaid coverage. Home care may substitute for less available forms of care in rural areas, so it is essential that policies continue to support this important care option. Despite federal and state policies that have encouraged community-based and in-home services as economically sound alternatives to institutional care, rural elders have a narrower range of care options and fewer community-based alternatives available to them. Thus, higher utilization rates of nursing home services continue in rural settings (Coward et al., 1996).

The migration of young and middle-age adults has adversely affected the economy of rural communities, reducing both per capita income and tax dollars available for education and health-care services. The myth that most rural elders and their families live on comfortable, spacious homesteads (Krout, 1994), has been replaced by the reality that many live in antiquated, substandard housing, located in limited access areas without public transportation. Older adults and their caregivers who reside in rural communities are more likely to be poor, to have less formal education, and to depend more heavily on Social Security benefits after retirement (Rogers, 2002). They are less likely to have pensions, savings, investment income, or health insurance coverage than their urban counterparts (Coward et al., 1994; Schwenk, 1994). Older women, who are the primary caregivers in rural areas, have the greatest economic vulnerability (Rogers, 1998).

Elder Care

Informal caregivers of the elderly typically begin their "caregiving careers" with the provision of *indirect care* services, that is, assistance with instrumental activities of daily living (IADLs) such as transportation, household maintenance, meal preparation, and financial management. As care recipients become frailer and their functional abilities diminish over time, caregivers tend to provide more *direct care* services associated with activities of daily living (ADLs) such as assisting with mobility, dressing, eating, and toileting. Although friends and neighbors who live nearby may be enlisted to help with less personal care activities such as grocery shopping or transportation, family members, especially spouses and then adult children and children-in-law, are expected to provide most of the needed care services. Older rural women are at particular risk, as their support network may be small and family members may not be readily available to care for them (Barnes, 1997).

Rural caregivers are older than their urban counterparts, report more health issues associated with the demands of caregiving (Roberto et al., 2001), and consider themselves to be in worse health than people in the general population (Sanford and Townsend-Rocchiccioli, 2004). Spousal caregivers of rural elders may themselves be physically frail or cognitively impaired, and adult children are often urban-dwellers who can discharge their caregiving obligations only on weekends. A survey conducted by the National Family Caregivers Association (2000) reported that while 52% of caregivers provided direct care services and 42% gave medications and monitored vital signs, almost two thirds of those surveyed did not live with the care recipient. The transition to the role of care provider may be particularly difficult for adult children, especially those who must cut back on or relinquish their jobs, resulting in financial hardship (Henderson, 1992). A recent survey found that long distance caregivers miss an average of 20 h of work per month, spend $392 per month on travel and caregiving-related expenses, and almost half rearrange their work schedules to tend to caregiving responsibilities (MetLife, 2004).

Archbold (2005) notes that the health-care system delegates a tremendous amount of care to families without adequate structures in place to support caregivers in their role. Three commonly held, but false, societal assumptions are embedded in the social expectation of family care for elderly persons with dementia (Kelley et al., 1999). Although not specific to them, these assumptions hold true for caregivers of cognitively impaired rural elders, and include that family members: (a) are not providing enough care; (b) have innate skills and knowledge about how to provide care; and (c) have access to the appropriate resources for the provision of care. Data from a National Alliance for Caregiving and AARP (1997) also serve to refute these assumptions. The survey documented that 59% of caregivers of older adults received no instruction on how to perform caregiving activities for their ill family member, and that caregivers of persons with dementia needed someone to talk with and help with understanding long-term care resources. Other challenges faced by rural elders and the persons who care for them are the complexity and confusion of the formal health-care system and associated reimbursement policies, as well as being put on waiting lists for services that are needed immediately (Connell et al., 1996). This challenge becomes even more acute as elders move across levels of care (e.g., from hospital to home or nursing home) (Magilvy & Congdon, 2000). In rural areas these difficulties are compounded for long-distance caregivers, who must often make health-care decisions and implement actions without onsite assistance.

Needs of Rural Caregivers of Elders

Informal caregivers in rural communities need a core set of skills that enable them to accurately monitor and interpret symptoms, successfully manage medical regimens, provide hands-on care, find and utilize appropriate resources, and make sound caregiving decisions, all while providing affective support and encouragement to a chronically ill or disabled elder (Schmall, 1995; Schumacher et al., 2000). To meet these broad-based needs, caregiver assistance programs traditionally combine information on aging and chronic illness with skill training on providing home care, as well as affective support, counseling, and periodic respite for the caregiver (Toseland et al., 2001). These programs can be delivered through individual, group, and/or family counseling sessions, in-home caregiver skill training sessions, and/or a wide array of technologies (e.g., telephone contacts, computerized training programs, two-way video interaction systems) (see chapters in this volume by Chwalisz et al., and Yellowlees et al.).

Effective Programs for Caregivers of Rural Elders

Based on a review of the literature and clinical and research experience in this area, we developed the “R.U.R.A.L. Caregiver Program Planning Model” program, outlined below. The model (see Table 3.1) was first proposed in an issue brief

Table 3.1 The R.U.R.A.L. elder caregiver program planning model

	Desired program characteristic	Program planners must ensure rural caregiver assistance programs:
R	*R*elevance	involve caregivers in identifying needed program services
U	*U*nity	enlist multidisciplinary program planners (nurses, social workers, physicians, ministers, other community service workers) to insure the new program articulates with existing programs/services in the community
R	*R*esponsiveness	are responsive to the ethnic and cultural identity of elders/caregivers in the community
A	*A*ccess	enhance program access for caregivers/elders by timing, transportation and location of new services
L	*L*ocal leadership	include local leadership in supporting and publicizing the program (nurses, social workers, physicians, ministers, other community service workers)

(Buckwalter & Davis, 2002) for the "National Family Caregiver Support" program and is described and expanded here with permission of Rick Greene, MSW, U.S. Administration on Aging. Desired program characteristics: *R*elevance, *U*nity, *R*esponsiveness, *A*ccess and *L*ocal leadership, are illustrated using examples from successful programs for caregivers of rural elders.

Relevance

The concept of program relevance mandates that planners and service providers actively involve caregivers themselves in identifying and evaluating the services they need, rather than assuming that "professionals know what's best" for them. Difficulties in fulfilling the caregiving role are complex and multidimensional. Whereas some families are burdened by direct care responsibilities, others easily adjust to this aspect of caregiving, and are more strained by concerns over finances or obtaining the assistance they need from the health-care system (Archbold, 2005). Health-related goals should reflect these differences, and be developed with, instead of for, rural elders and their caregivers; service providers must ask caregivers what strategies work for them (Lee, 1993). One of the best ways to involve caregivers is by making home visits part of the assessment process. Not only is this more convenient for most caregivers of rural elders, but it also allows providers to assess for substandard housing and safety needs, and to determine preferred methods of obtaining information (Lee, 1993).

A number of in-home caregiver support programs have demonstrated positive outcomes for elder caregivers. Buckwalter et al. (1992) conducted a 4-year multisite rural caregiver study to test the effectiveness of an in-home caregiver training intervention based on the Progressively Lowered Stress Threshold (PLST) Model. The experimental intervention provided training to facilitate caregivers' knowledge of dementia and development of competence in the management of care recipient behaviors they found problematic. Importantly, the training was individualized based upon expressed caregiver needs, as determined by administering the "Behavioral Assessment for Low

Stimulus Care Planning" instrument at baseline (during the first in-home visit). Findings revealed that caregivers who received the individualized in-home training intervention were more satisfied with the caregiving experience, reported decreased levels of burden, uncertainty, and depression, and were also less upset by behaviors of the care recipient (Gerdner et al., 2002; Stolley et al., 2002).

Archbold and associates (1995) tested the *P*reparedness, *E*nrichment, *PR*edictability (PREP) system for in-home family caregivers of elders. Through a Medicare waiver provision, families in the PREP group received 3–6 months of care from specially trained nurses, including systematic assessment, family focus, local and cosmopolitan knowledge, individualized interventions using multiple strategies, therapeutic relationships, and transitions. Subjects in the control group received standard HMO and in-home health agency care. Caregivers who received the PREP system reported higher care effectiveness and overall usefulness of the in-home staff. The intervention also saved an average of $3,800 per family over a 3-month period through cost offsets (Miller et al., 1996). Archbold recently noted that a distinctive feature of her program of family care research is that it "uses an interactionist and role theory perspective to incorporate views of elderly individuals, family members…" and "that 'one-size-fits all' interventions, a standard approach in many health care systems at this time, will not be effective in preparing and supporting families" (2005, pp. 2–3).

Asking for and receiving help is not the norm in many rural areas and many caregivers have difficulty articulating their needs. Successful programs will be those that assist the elder and their caregiver to problem solve while maintaining autonomy, dignity, and privacy (Lee, 1993). Therefore, a final example of the program characteristic of "Relevance" comes from the work of Robinson (1988, 1990) who developed a successful social skills training model for caregivers of elders that enables them to learn specific skills they need in order to mobilize help from their social networks. The training program focuses on assertive social skills such as how to give instructions when help is offered, how to make a request for help, how to express appreciation for support, as well as how to say "no." Written materials reinforcing key points augmented individual counseling sessions. Acquisition of these skills yielded increased social support and lowered caregiving burden. Other control-enhancing interventions, such as stress management classes, may also assist caregivers to better master their environment and improve their quality of life (Lee, 1993).

Unity

To facilitate unity, linkages must be formed and new programs integrated with existing community services, to avoid competition or duplication of extant programs. Importantly, use of existing structures, services, or providers as a foundation for development of new programs enhances their acceptability and longevity (Lee, 1993). Both the PREP and PLST caregiver programs described above took the principle of unity into consideration. In the former, the PREP intervention was developed within the context of an organized health system, in that elderly persons and their caregivers were members of the health plan and received most or all of their care from it (Archbold, 2005). In the PLST intervention, as part of both the experimental and comparison protocols, caregivers received referrals for local support groups and case management services (Buckwalter et al., 1992).

Another application of the concept of unity comes from the "Building a Seamless Delivery Dementia Care System in Rural Iowa" project which was a collaborative effort between the state's Department of Elder Affairs, the University of Iowa, Area Agencies on Aging (AAAs), Alzheimer's Association chapters, and Resource Link of Iowa. This Administration on Aging (AoA) funded project, led by Dr. Janet Specht, was designed to provide expanded in-home services to rural Iowans affected by dementia and their caregivers. The project used a community organization model to help rural communities develop care systems that met their unique needs. Additionally, an in-home, nurse care managed delivery system was evaluated for its impact on care recipient and caregiver well-being. Four (experimental) counties received nurse care managers (NCM) who were specially trained to provide in-home services, education, and support to persons with dementia and their caregivers, with a particular emphasis on building capacity in the caregiver by focusing on stressors they identified (see Relevance criteria). In terms of program unity, the NCMs worked with local case management systems to coordinate available services, refer clients to funding sources, assist with community development programs, and report to the AAAs. Caregiver outcomes in the experimental counties included enhanced caregiver well-being, endurance, and ability to manage stress.

Responsiveness

Successful programs must be responsive to the ethnic, cultural, religious identity, and traditions of the elders and caregivers they aim to serve. Lassiter (1992, pp. 30–31) set forth five tenets of community development that are of special importance in rural areas, and applicable to programs that support elder caregivers: (a) citizen participation and partnership are essential for community improvement and growth; (b) the focus of work should be on local concerns; (c) citizen groups are utilized in community development; (d) implementation is suitable to the locality; and (e) process outcomes for the community are as important as task undertakings. Because of the heterogeneity of rural environments and the many subcultures of elders and their caregivers living within those environments, service providers are challenged to develop a working knowledge of the characteristics of the local environment (Lee, 1993).

Faith-based initiatives provide one responsive option for caregiver support in rural settings. Dr. Karen Robinson developed a successful dementia-specific Volunteer Caregivers Program (VCP) that was an outgrowth of the Volunteer Interfaith Caregivers of Kentuckiana. This support program began when representatives from various religious congregations and a local Alzheimer's chapter joined forces and developed a vision to train volunteers to provide in-home respite to keep caregivers connected to their support groups. The VCP provides support services to elder caregivers at no charge, including assessment, care planning, education, evaluation, information and referral, and volunteer support. The VCP also provides free public services such as memory screening and community education programs.

Two assumptions relevant to the concept of community responsiveness underlie the approach of the "Building a Seamless Delivery System" project described above: (a) if services are to be accepted within rural communities, they must be designed by the community; and (b) if the community values the services, they will refer neighbors to them. Other successful outreach programs (Connell et al., 1996) have also been based on a community development model, which is a process of working collaboratively with community members "to assess the collective needs and desires for healthful change and to address these priority needs through problem solving, utilization of local talent, resource development and management" (Lassiter, 1992, p. 30). These programs build upon community strengths in designing services for rural caregivers, including: (a) community action and cooperation; (b) close-knit ties and long-established roots; (c) dedication and caring for residents in rural areas; and (d) strong cultural identity.

Access

Access is a critical component of programs that support caregivers of the rural elderly. Access can be enhanced by attention to timing, location, transportation, and the publicizing of services, as well as consolidation of programs into multipurpose packages that serve a broad array of needs and populations (Lee, 1993). For example, a geriatric mobile dental unit staffed by students from an urban Health Sciences College could also be expanded to provide immunization services to elders and their caregivers in rural areas.

The AoA's National Family Caregiver Support Program has initiated a number of programs targeting both middle-age rural caregivers in the workforce as well as older spouses. In Iowa, under the leadership of Betty Grandquist and the Iowa Association of Area Agencies on Aging (AAA), a multifaceted project is underway to assist caregivers in rural settings. This project pays special attention to access issues, and combines a case management approach with screening and referral to the nearest AAA, where a Family Caregiver Expert, who is knowledgeable about community resources, takes over. A software program developed by the Atlanta Regional Commission provides a standard information and assistance network, a directory of resources, and matches caregiver needs to available options, although each AAA is expected to develop support services responsive to the needs of caregivers in their area. In addition, a toll-free number was established to create a single point of entry for services.

The Family Caregiver Support Program, operated by Elder Services in Johnson County, Iowa is another program that is sensitive to access issues. It is comprised of two primary components: Information and Assistance (I & A), and Family Caregiver Counseling. The I & A specialist receives inquiries from a nationwide toll-free telephone number and provides callers with information about appropriate state or local caregiver resources. The Family Caregiver Counseling specialist works with family caregivers in their homes to assess their needs, develop a plan to address problems, and enable caregivers to successfully maintain their role. Typically, a short-term counseling model (usually 1–6 meetings) supports caregivers during times of transition, and assists them in making important decisions, although crisis intervention services are also available. The counseling specialist may provide assistance in the form of I & A, skill building (e.g., communication, caregiving skills), short-term counseling, family mediation, and arrangement of appropriate community services and resources. Information is targeted to caregivers' unique needs, and help is provided to alleviate their sense of isolation and to feel supported in their role. The majority of referrals come from case managers who oversee services to clients involved in the Case Management Program for the Frail Elderly. The counseling specialist addresses caregiver needs, which may go unnoticed in the case management program.

In addition, the PREP intervention discussed earlier (Archbold, 2005) addresses the access criterion of timing by focusing on families during key health-care transitions that are indicative of health decline. These are critical times when the health system often shifts care responsibilities to family members who may require new skills in order to be successful in their caregiver role.

Local Leadership

Virtually all of the successful caregiver assistance programs highlighted in this chapter include local health-care professionals, church groups, civic leaders, and other community service workers in supporting and publicizing their respective programs. For example in the "Building a Seamless Delivery System" project, investigators found that when the Nurse Care Manager was from the same area she/he served, the project was more successful. In many cases, the nurse became what one aging network professional described as "a trusted relative," and was easily integrated into the community's perception as a "helping professional." This integration fostered referrals from sources such as the local bank, churches, service and social clubs, and others in the rural town. Several of the rural counties enthusiastically embraced the community action programming. The fact that it was developed within and by their community exclusively became a source of pride, supporting the notion that programs that are clearly identified with community needs are more acceptable than those that are developed by "outsiders" and "imposed" on elders and their caregivers.

Recommendations from rural family caregivers who participated in a Community Outreach Education Model program (Connell et al., 1996, p. 24) also support the need for local involvement and leadership. Caregivers advised on the need to target educational interventions to information and referral agencies, government and law enforcement agencies, and the public using outreach to service clubs, churches, the local business community and community centers. They also suggested development of a speaker's bureau as a mechanism to disseminate information to the community (see Access criteria). Community involvement, a sense of ownership and group identity, and a commitment to the program were viewed as vital to long-term change in the response of people to caregivers of persons with dementia in rural communities.

In summary, consultation with experts in the field and a review of effective programs suggest that in order to be successful developers of elder caregiver support and training programs must attend to and respond to a number of factors.

1. Program developers must take into consideration the diverse needs of rural elder caregivers and the characteristics of their social networks.
2. Programs should be suitable for both non-kin as well as kin caregivers, given that rural elders often do not have kin nearby.
3. A variety of approaches should be used to alert caregivers to available services, including brochures, radio and TV spots, educational programs, and web sites. A multimedia consumer publicity "blitz" is a good way to kick off new programs or projects.
4. Given the lower level of education and health-related knowledge common in rural areas, program developers should provide a variety of informational programs for caregivers on topics such as healthy aging, symptoms and management of common chronic diseases, managing medical and drug regimens, emergency care, and marital and family issues around long-term caregiving.
5. Because the demands of caregiving can take an emotional toll on caregivers, programs should offer preventive as well as supportive counseling services for distressed/depressed caregivers.
6. Providers are encouraged to avoid labels that may make programs socially unacceptable or stigmatizing for rural caregivers.
7. Because of distance and access barriers, programs should provide access to transportation services to community-based program offerings, as well as home visitation services for individual caregivers.
8. As caregivers often neglect their own health-care needs, program developers should offer caregiver "health promotion" programs (e.g., blood pressure checks, pap smears, mammograms) during weekday, daytime hours so busy caregivers can combine self-care activities for themselves with a doctor's appointment for the elder during a trip into town.
9. To facilitate communication and coordination, programs should provide telephone contact and referral services for urban-dwelling family members who are long-distance caregivers for rural elders.
10. Given that local investment/ownership is critical to program success, developers should make annual fund-raising activities a regular part of programs.
11. To enhance the sensitivity and acceptability of programs, they should be staffed by professional, paraprofessional, and volunteer personnel who are both knowledgeable about and sensitive to community culture and traditions as well as health-care problems and service needs.
12. Programs should embrace flexibility and a common sense approach to the allocation of funds, avoiding, whenever possible, bureaucracies that impede getting the money to where it is needed most.

Table 3.2 Practice, research, education, and policy implications for helping elders and their caregivers in rural communities

	Current status	Future directions
Practice	Both direct and indirect (IADLs) health-care services are less accessible, less specialized, and more costly to deliver in rural areas. Fewer "home and community based" options.	• Comprehensive needs assessment to develop rural caregiver assistance programs that are available and acceptable and that provide health promotion for both kin and non-kin caregivers • Address challenges for long-distance caregivers of rural elders • Use telehealth strategies/outreach models to address changing service needs over time • Create articulated models of caregiver assistance programs between urban and rural health-care centers
Research	Barriers to translation of evidence-based models to practice (both caregiver assistance programs, in-home caregiver support)	• Develop, implement, and evaluate "promising practice" models of caregiver assistance that are designed to be sensitive to the social, ethnic, and geographic characteristics of rural communities • Collaborate with urban academic centers for research on rural elders and their caregivers
Education/training	Insufficient number of health-care professionals with geriatric, management and mental health expertise practicing in rural communities	• Encourage health profession schools to include rural family caregiving courses in their curricula • Give high school and community college students course credit for visiting and working with frail elders and their caregivers • Project the need for rural health-care service providers by discipline and offer more postgraduation incentives for providers who practice in rural communities • Use recommendations from recent IOM report on rural health issues as foundation for education, recruitment, and retention of rural health-care providers
Policy/advocacy	Third-party payor restrictions for case management services, reimbursement levels, excessive regulations, and paperwork	• Policies to promote awareness, access, affordability, adequacy, appropriateness and acceptability of rural caregiver programs • Implement meaningful data collection systems for caregiver needs assessment and follow-up • Expand elder care insurance coverage to include informal caregiver education and skill training • Provide state and federal funding for rural health centers through "dollar matching" grant mechanisms that encourage rural communities to participate in fund-raising and ownership of local caregiver assistance programs

Additional practice, research, education/training, and public policy issues, both current and for the future, related to helping rural elders and their caregivers, are summarized in Table 3.2.

Conclusions

Numerous conditions in rural areas converge to make service delivery to rural elders and their caregivers difficult. These include poverty, isolation, difficulties with transportation, sparse and scattered population, resistance to innovation and too few human service agencies, trained professionals and health-care resources. To be successful, service providers must offer rural caregivers better coordination of services, improved communication among local agencies (Connell et al., 1996), consistent relationships with providers they trust, and improved access to information (Davis & Magilvy, 2000). In order to overcome the attitudinal and logistic barriers to service delivery in rural areas, community-based outreach efforts must include local leadership and representation from health-care professionals, service providers, staff of community organizations and volunteers. Such cooperative efforts help to "develop community competence and empowerment, and provide a greater understanding of cultural values and beliefs" (Connell et al., 1996, p. 16).

Effective rural caregiver support programs must get needed services to often-isolated rural elders when and how they need them. Services should be caregiver, not provider, driven, and flexibility should be the watchword. Like the projects highlighted in this chapter, effective programs must be available, accessible, accommodating, acceptable, and affordable. The R.U.R.A.L. model was set forth as one way to conceptualize essential characteristics and persons to involve when planning support and training programs that meet the diverse needs of rural caregivers while accommodating the characteristics of their social networks.

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Chapter 4
Care for Children and Youth in Rural Areas

Susan K. Walker and Kathy L. Reschke

Each week in the United States an estimated 6.4 million children under 5, or 55% of infant and preschool-aged children spend time being cared for by someone other than their parents (Johnson, 2005). Another 7.4 million are in the care of relatives. Many of these children enter non-parental care by 11 weeks of age and are in care for close to 30 h a week. In 2001, 8.6 million rural children in elementary school were in before and/or after school care (U.S. Department of Education, 2004). For infants and school-aged children, relative care is the most frequently used child-care arrangement. Some research indicates that this pattern of relative care use is even more prevalent in rural areas (Hunts and Avery, 1998). Therefore, for a significantly large number of rural families, child care provided by a relative is an important daily occurrence of family caregiving.

In this chapter, we examine the non-parental care of children and youth in rural areas, with a particular interest in child care provided within the family system. This chapter will offer a foundation of information from the research literature about rural families' child-care options, factors that influence rural parents' choice of child care, and the challenges to providing quality care settings for rural children. This will be supported by information about the practice of child care in rural areas, and education and training programs currently available to professional providers and family caregivers. Current policy perspectives for rural families primarily center on assistance to families in paying for child care. The second section of the chapter will turn to future directions for practice and education in rural child care, needs for research, and avenues for policy. We start, however, with a discussion about child care and family caregiving to align the focus on children's care in rural areas with the other chapters' perspective on family caregiving, particularly those chapters that address the interests of older family members.

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Family Caregiving for Rural Children Within the Continuum of Child-Care Options

Unlike family caregiving that may be provided across the life span to a child to assist with tasks of daily living, care for children in this chapter is defined as the stable arrangement that parents make for another individual to be responsible for their child's well-being while they are working, in school, or otherwise cannot be with them. Child care takes place in a variety of settings and is provided by a variety of individuals. These child-care settings can be placed along a continuum of formality and structure (Porter & Rice, 2000). At one end are parents who care for their children within the scope of their overall child rearing and parents who each provide care for their children while the other is working. Closely related to this is relative care: care is provided in a home atmosphere by someone related to the child, often provided with no expectation of compensation, and is offered as a service to the parent. At the other end of the spectrum are child-care centers: held to regulatory standards, staffed by trained paid professionals, operated on business principles, and supported by fees and tuition paid by parents, and in many cases, by government funding.

There are parallels between care for children within a family system and family caregiving. Along a care continuum, family caregiving for children or child care within the family system may differ by location, formality, and provider of care for the elderly or disabled (Walker et al., 1995). Demographically, the average age of the child caregiver, likelihood of being female and hours of work in providing care is similar to that of the family caregiver (Walker & Karushkina-Drivdal, 2005). Other parallels include caregiver motivation to fulfill familial responsibility (Zinsser, 1991) and stress on the provider. Recent studies of grandmothers identify them as a, if not, the, significant source of backup child care (NACCRRA, 2008). And studies of those who are the primary child-care provider for their preschool-aged grandchildren have suggested health risks associated with this work (Lee et al., 2003). In addition, as with other types of care, child caregiving shared between mother and relative can potentially cause relational strain within the family system. Tensions most often arise when there are disagreements about discipline and routines such as feeding, the amount of time that care is required, and questions about roles when the caregiver spends as much, if not more, time with a child than his or her own parent (Porter, 1998). Our study of low-income mothers using grandmother care suggests, however, that even when disagreements arise, mothers may feel constrained to maintain the child-care arrangement because it is the most affordable and flexible choice (Reschke & Walker, 2006).

As this chapter will suggest, the choice for child care is similarly based on need of the individual in care, preference by the family, and availability of care options. As with family caregiving, a family-centered model of child care looks at the perspective of need for care by the recipient (child, elderly person) and the ability of the provider to offer care services. It also respects the contribution that familial relationships make to the recipient's well-being, sometimes in ways that professionals cannot, and recognizes that the caregiver's influence on the child is strengthened when its members are supported, connected, empowered, and respected (Dunst et al., 2002).

Because this chapter's focus is on the provision of care for children in rural areas, and because the spectrum of care options includes family members and professionals, we will use the words "provider" and "caregiver" interchangeably.

Current Research Perspectives on Rural Child Care

Factors Influencing Child-Care Choices

Practical Needs for Care

With increasing numbers of mothers in the workforce, the need for child care has continued to rise in the past several decades. More than half (55%) of mothers with infants are employed (Bachu & O'Connell, 2001). In 2004, nearly two thirds, or 61.8% of women with children younger than 6 were employed. Three quarters of women in the labor force with children ages 6–17 declined slightly, from 77% in 2001 to (U.S. Department of Labor, 2005). Predominantly rural states report higher percentages of women in the labor force than their rural counterparts. Parental employment creates a need for children to be in others' care, yet child care is also a system that, when stable, flexible, and affordable, helps to maintain employment, thereby supporting family economic well-being. To understand difficulties around employment in rural areas, one must consider the critical value of a sound and secure system of available child care.

Families choose child-care arrangements that are most feasible. Child care must be reliable: low-income mothers' unstable child-care arrangements are a frequently cited challenge to finding and maintaining employment (Scott et al., 2005). Child care must be affordable, available during the hours needed, and accessible. Research suggests that the primary characteristic needed for child care to work for low-income families is flexibility (Henly & Lyons, 2000). Low-wage jobs tend to require working evening and weekend hours, have unpredictable schedules, and offer few if any parent-friendly benefits. For a mother working this type of job, particularly a single mother, it is imperative that her child-care provider be flexible in the hours she or he is willing to provide care and willing to care for the child when unforeseen problems arise, such as a child's illness or unexpected overtime. Informal child care, and particularly relative care, is in most cases the most flexible of all options. Relative care is also imminently feasible because of cost: studies indicate that relatives rarely receive or want monetary compensation (Hunts & Avery, 1998).

Benefits of High-Quality Care

Feasibility, however, is not the only factor that influences parents' choice of child-care arrangement. Two trends indicate that parents, regardless of income, desire care for their children that provides a developmentally stimulating environment. First, the number of children from low-income families in center-based care markedly increases when children reach preschool age, due primarily to the availability of publicly funded care for preschoolers that is absent for younger children (Fuller et al., 2002). In our own study of low-income, rural mothers in 11 states, formal care was almost exclusively center-based and used primarily for 3- and 4-year-old children (Walker & Reschkem, 2004). This strongly suggested that publicly funded preschool programs such as Head Start were the only possible formal care available to low-income, rural mothers and were chosen and trusted as a high-quality educational environment for their children. Parents, therefore, seek care that provides a nurturing, stimulating environment for their children as well one that is functionally possible.

Second, regardless of where child care takes place, research overwhelmingly shows that higher-quality care benefits young children. Children in better quality child care/early education programs have stronger language, pre-mathematics, and social skills than those in lower-quality classrooms, and have better relationships with their teachers and more positive self-perceptions (for a review, see Lombardi, 2003). Impacts on children's cognitive and social development result regardless of child's gender or mother's level of education. Quality care has an even greater impact on "at-risk" children's language skills and self-perception. Additionally, quality early outcomes hold up. Good programs can affect children's long-term success in areas such as school achievement, higher earnings as adults, and decreased involvement with the criminal justice system (Garces & Curie, 2002).

Similar results are found for school-age children. Mahoney et al., (2005) report on the potential benefits of formal after-school arrangements for children living in poverty. A longitudinal study of 599 low-income children determined that those in formal after-school programs had significantly higher academic achievement and motivational attributes than their counterparts in less structured after-school settings, including those in self-care or sibling care.

Child-Care Challenges for Low-Income and Rural Families

Ideally, child care for rural families, as with other families, needs to be: (a) available for the age of the child(ren); (b) of a high quality for children's learning and development; (c) accessible to home and/or work; and (d) offered at a price within the families' ability to pay. Each of these issues is more difficult for low-income families and a particular challenge for families who live in remote areas. What follows is a brief picture of the realities of rural families' options when considering caregiving for their young and elementary school-aged children.

Availability

Sparsely distributed populations result in fewer regulated group-care options and higher transportation demands (Beach, 1997; Colker & Dewees, 2000; Collins et al., 2008; Shoffner, 1986). A 1989 National Governors Association survey determined

47 states with rural areas in which families had difficulty obtaining regulated child care for their children. Public data about the number of regulated child-care slots available to children in rural counties indicates the minimal number of regulated child-care “slots” relative to the need. For example, in Tillamook County, Oregon, the availability rate is 16% (Oregon Child Care Research Partnership, 2002). In many counties there are a minimal number of child-care centers or homes. In Bath County, Kentucky, for instance, there are no centers serving infants and toddlers. In Dorchester County, Maryland, as reported by several mothers in interviews, one of the two centers caring for infants in Cambridge, the county seat, closed due to charges of infant abuse (Walker & Reschke, 2004). A recent report on children in Arkansas and Oklahoma (Oklahoma Institute for Child Advocacy and Arkansas Advocates for Children and Families, 2004) reported that there were three children competing for every child-care space available in those two states.

Quality

Positive cognitive and social outcomes for children result from structural aspects such as the number of children in a classroom or family child-care home and the ratio of children to adult caregiver. An appropriate curriculum for learning promotes development of the “whole child.” Quality staff adequate training and experience, are well-supported through adequate wages and benefits, and stay in their jobs (NICHD Early Child Care Research Network, 2002). States with more demanding child-care licensing standards, and the staff to maintain them, have greater numbers of high-quality centers. The quality of early care settings in rural areas has been examined in light of analyses that reveal rural children to be behind their urban counterparts in pre-academic skills (Grace et al., 2006). The Cost, Quality, and Child Outcomes Study team (1995) determined that rural states have fewer state-licensing employees and longer distances to travel, making it more difficult to enforce standards and to maintain specialized training for child-care professionals. Additional studies suggest that the quality of care in rural areas may be lower than that in urban or suburban areas due to lower wages earned by rural child-care providers and a less educated and trained workforce (Atkinson, 1994; Beach, 1997; Collins et al., 2008).

The heavy reliance on relative and friend caregivers in rural areas is another reason for reports of lower-quality care, in aggregate. In general, studies comparing center-based child care and child-care provided by relatives and friends have found the latter to provide less intellectual stimulation and social skill development (Galinsky, Howes, Kontos, and Shinn, 2000). In their study of 11 rural counties, Thornburg et al., (1997) found that, although parents’ reports of satisfaction with their child-care providers was high, kindergarten teachers found no differences in children’s school readiness between those who had been in child care and those who had not. They attributed their findings to factors related specifically to rural culture. Thornburg et al. suggest that the tradition of self-reliance and not asking others for help with personal problems may create a barrier to acknowledging the need for assistance with child-related concerns. Adding to this issue is the finding that the ability to care for children is one in which many women, including professional family child-care providers, feel they are experienced and have little need for outside help (Walker, 2002). Furthermore, rural relative caregivers for children may be reluctant to engage in programs that offer information and support, preferring to keep conversations about child rearing within the family, or at most, venture no further than their own home for assistance (Southern Maryland Child Care Resource Center, 2003).

Access to Care

In our analysis of data from 11 states in a study of rural low-income families after welfare reform (Walker & Reschke, 2004), mothers' child-care choices were restricted by scarce regulated sources, but also by inflexibility in formal child-care options. Many of the part-time jobs available and held by women in rural areas are in service jobs, such as fast food and housekeeping; jobs that often call for nontraditional shifts. The average number of hours in part-time work was just over 20 per week. With these schedules, mothers may not be able to find regulated care available – or may be reluctant to pay for a full-time slot when they need less than full-time care. A benefit of the use of family and friends for care is the accommodation for mothers' short or flexible work schedules (Brown-Lyons et al., 2001; Folk & Beller, 1993).

Access to child care involves families' knowledge of how to find child care, as well as the location and transportation to a site outside the home. Many rural mothers report that they do not know how to find formal child care (Walker & Reschke, 2004). Physically getting to child-care sites is also a potential barrier. The location of child-care options in counties is among the most limited of public information.

Two counties in one state may serve as an example, however. Maryland (Maryland Child Care Resource Network, 2010) maps the locations of regulated child-care centers and family child-care homes in each county. In Dorchester County in 2010, there were twelve child-care centers and 55 family child-care homes; nearly all, however, were clustered around the city of Cambridge. The nearest regulated facilities outside of Cambridge were 30 miles to the north or 80 miles to the southeast. In Garrett County on the western side of the state, from the cluster of regulated settings in Oakland, the nearest populated area with center or family child-care homes was 50 miles away in the next county. If families live and work between these clusters of child-care facilities, and transportation is not available, they are practically bound to find alternative arrangements.

Cost

The cost of regulated care clearly impacts use by low-income families (Mitchell et al., 1992). In an assessment of school-age child-care needs among rural Oregon children, Hobbs and Chang (1996) determined that 71% of school-age children were in need of care, but affordability was a barrier. One study revealed that a year of center-based care costs more than a year of public college tuition in all but one state (Schulman, 2000). In 43 rural areas where data was collected, the annual cost of child care for a preschool-aged child ranged from $3,000 to $6,000. In over half of the rural areas, the cost of care for an infant was over $4,500 per year. And, although in comparisons with urban areas, rural employed mothers technically pay less for child care (Smith, 2006 estimated the difference to be $32 a week for preschool-aged care), in relative terms rural families (the portion of the family income) may pay more for care. In our 11-state study, comparing median family incomes with the average costs of care reported for regulated facilities or providers allowed us to calculate the potential impact of regulated care costs on families' ability to pay. Families in the study with at least one infant or toddler had a median monthly income of $1,153.84, or $13,846 per year. Paying for full-time, center-based care for this infant (at an average of $5,144) would consume 37% of the family income. For many rural families, this cost exceeds other household costs, such as housing and utilities. These are fixed costs that make the high price tag on child care impractical for many families.

Summary of Research on Considerations Rural Families Face When Selecting Child Care

Public data and research reports indicate that adequate regulated care is not available to meet the potential need in the rural counties, and limited data suggest that regulated options are clustered around populated towns many miles apart. Minimal use of regulated care, in favor of care by relatives and friends is linked to reports of lower quality of child care in rural areas. Quality also is compromised by inadequate systems of support and oversight of state regulations. Even if regulated care were more prevalent, the cost of regulated, nonpublicly provided care would consume an unrealistic portion of the family income for low-income families. In response, programs, education, and policies are in place to help rural families secure quality care for their children in arrangements that are convenient and affordable.

Programs and Practices that Address Rural Child-Care Issues

National Programs

Issues of making formal, regulated child care higher quality, more accessible, affordable, and in supply to meet rural parents' needs have been grappled with for decades. Public and private initiatives at the federal, state, and local levels assist parents in arranging care that meets employment needs, and support children in their learning and development. This section will describe a sampling of many of the diverse programs throughout the United States. It is important to note that while some programs are administered through federal dollars, most rural programs that boost quality and availability of child care in rural areas depend on state allocations of public funds, grant receipt from private foundations, or innovative collaborations between local agencies.

Head Start programs are available in rural counties and tribal territories across the United States, offering a nationally administered federal program with standards for educational excellence for young children. Administered by the U.S. HHS, Administration for Children and Families, the Head Start Bureau offers one program that particularly meets the needs of rural families. The National Migrant and Seasonal Head Start Quality Improvement Center provides culturally and linguistically appropriate training and technical assistance to Migrant and Seasonal Head Start programs nationwide.

The Twenty-First-Century Learning Centers (21CCLC) initiative through the U.S. Department of Education, originally authorized under Title X, Part I of the Elementary and Secondary Education Act (ESEA), provides funding for schools to stay open longer and provide spaces for elementary- and middle-school children to be safe and continue learning in after school hours (http://www.ed.gov/programs/21stcclc/index.html). The 21CCLC program is the only federal funding source for out-of-school programs. The funds must be allocated to the state's poorest communities. In 2001, there were 1,600 grantees, an estimated 58% of which served rural communities. The changes to the grant in 2001 actually reduced the number of rural communities that received support because the formula grant favored areas with a high concentration of low-income children, which is more commonly found in urban areas (The Finance Project, 2003). After-school funding is also possible through the Rural Education Achievement Program (REAP)'s Small, Rural School Grant Program. Title 1, Safe and Drug-Free schools are eligible for funding (http://www.ed.gov/offices/OESE/reap.html).

The U.S. Department of the Interior, U.S. Department of Justice, U.S. Department of Education, and U.S. Department of Health and Human Services provide support for programs assisting tribal governments. Some of the programs can support out-of-school programs in these communities. The following are examples of initiatives that can be used to provide support for out-of-school programs for children: Indian Child Welfare Act, Johnson O'Malley Program, Indian Education Grants to Local Education Agencies, and the Tribal Youth Program (http://www.ojjdp.gov/typ/).

Federally funded community development and housing assistance efforts aid in developing new child-care businesses and maintaining existing center- and family-based programs. The U.S. Department of Agriculture (USDA) National Rural Development Partnership brings together federal, state, local, and tribal governments along with private for-profit and nonprofit sectors for the improvement of rural communities. The USDA's Rural Business Cooperative Service (RBS) works in partnership with the private sector and community-based organizations to provide financial and technical assistance to businesses and cooperatives in rural communities. The Rural Housing Service of the USDA includes programs that offer grants and loans toward the development of essential community facilities, including child-care centers (http://www.rurdev.usda.gov/rhs/rcdi/index.htm).

Although not intended to fund child-care program operations, the Child and Adult Care Food Program through the USDA is a source of federal funds that child-care and after-school programs can apply to, to cover the cost of nutritious food served to children at the care facility. After-school programs, for example, which enroll at least 50% children who qualify for free or reduced-price lunch are eligible for funding.

Local Programs

Many successful ventures build on public–private partnerships (The Finance Project, 2000) to increase the supply of child care in rural areas.[1] In Huntsville, Arkansas, for example, the Butterball Turkey plant identified the need for child care for its employees. Through collaboration with a local Head Start and regional child-care nonprofit agency, the plant financed in large part, the building of a child-care facility. The facility is available for employees, but also serves as an additional child-care site for the community. In several other areas where ConAgra employees live, the ConAgra Foundation supports early childhood initiatives, many of which extend beyond child-care services and address children's health and special needs. These initiatives include parent education, immunization, and literacy programs, and are supported through interagency collaboration at the local level. Additional spaces for child care are created through the use of existing space in churches, schools, and other public buildings rather than finding the financing to create separate structures.

Education for Caregivers: Increasing the Quality of Care in Teacher and Caregiver Education, and Staff Development

Quality of child care is influenced greatly by the training, education, and experience of its professional staff and family, friend, and neighbor caregivers. Perhaps the most tangible federal effort around professional training and provider support is through set-aside funds from the Child Care and Development Fund (see policy section below). States are minimally required to use 4% of the federal dollars toward quality enhancements in their states. These dollars support professional development and technical assistance.

Quality of care is also boosted through national child care and after school associations that have established credentialing systems that early childhood and school-age

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[1] A comprehensive list of rural initiatives and agencies to improve the quality and quantity of child care can be found at The National Child Care Information and Technical Assistance Center (http://nccic.acf.hhs.gov/poptopics/rural.html).

centers and family child-care homes can use to achieve standards of excellence in programming, staff development, and training, program administration, and parent involvement. The National Association for the Education of Young Children, for example, offers an accreditation to child-care centers. Technical assistance and small grants are made available to local areas, including rural communities and tribal regions, to help centers complete the steps in the credentialing process and pay accreditation application fees.

The USDA also maintains the Cooperative Extension Service (CES) through outreach efforts of land-grant universities, historically black colleges, and academic institutions in tribal territories. The CES addresses public needs with information and education within states and collaboration of resources nationally among cooperating states. Many of these states have specific initiatives around professional training for child-care providers and training after-school program leaders. Increasing use of computer technology in teaching has enabled the universities through CES to provide distance learning over the Internet and satellite communication. Some state efforts, such as Cornell Cooperative Extension (CE), offer informational support programs for family, friend, and neighbor child caregivers (Cornell CE, n.d.). Nationally, the 4-H Youth Development Program collaborates with Big Brothers and Big Sisters, J.C. Penney, and the Boys and Girls Clubs to strengthen after-school programs and specifically meet needs in rural areas.

State Resources

At the state level, child-care resource and referral networks offer distributed centers that provide training and technical assistance to local child-care facilities and workers, and aid parents in locating care for their children. A statewide, coordinated system allows rural state programs to collaborate and share resources, ensures standardization of service and quality, and maximizes available public dollars (Bailey & Warford, 1995). This system may best be provided by a state agency or nonprofit, but must give equal attention to less populated areas of the states, and allows individual tailoring of programs to address specific local needs.

Specific state and regional child-care projects aim to improve quality of professionals in rural areas. In New York State, for example, three rural counties are collaborating through The Early Childhood Professional Development Project to enact a comprehensive plan to enhance early care and education. The partnership has a special focus on child-care provider training. Several of their efforts include the recruitment of mentors to work with less educated and less experienced providers, providing scholarships and increasing salaries as supports to stay in the field and achieve higher levels of professionalism, and building public awareness for the need to educate and financially support child-care workers. As a result, a higher percentage of child-care workers attend continuing education training, and rural child-care centers are NAEYC accredited.

Local Resources

Regional programs also support quality through training initiatives for rural child-care providers. Recent efforts have begun to target relative child-care providers. An initiative through the Families and Work Institute, Sparking Connections (O'Donnell, et al., 2006), has provided funds to support regional efforts to enhance quality of informal child care by offering education and training, social support, and supplies and materials. Rural communities are included in the initial sites funded for the project.

Current Policies that Address Rural Child Care

Federal and State Programs

The most significant federal child-care policy that supports families' purchase of child care is the Child Care and Development Fund (CCDF) administered by the Child Care Bureau of the Department of Health and Human Services. The majority of the dollars from this program goes to states to set up a program that subsidizes the costs of child care for low-income parents. Given this latitude in policy administration, states vary greatly in procedures, including the establishment of payment and co-payment levels, and reimbursement rates to providers. An examination of rural states' policies and procedures about the administration of federal child-care subsidies reveals differing practices that may influence the use of child-care subsidies by some rural families and not by others (U.S. Department of Health and Human Services [US DHHS], 2007). For example, depending on the state, some rural families may have incomes too high to qualify for state child-care subsidies. In fact, the 11 least generous states in terms of income eligibility are primarily rural. In addition, 10 of the 12 states (84%) requiring in person applications are rural. This presents a significant barrier by causing families to find transportation and take time to arrive at subsidy offices.

Some states, like Minnesota have a high level of income eligibility, at 270% of the federal poverty level but other states, such as Wyoming or Kentucky have lower eligibility rates, 133% and 157%, respectively. Co-payment rates also differ across states. In California, regardless of income level, qualifying parents are not required a co-payment. In other states, co-pay is calculated based on family income and area market rates. Payment rates to child-care providers also differ widely across the states and within states. Rates may not be high enough for providers to be willing to accept subsidized children. In states like Oregon and Nebraska, the payment rate was below 75% of the market rate. Child-care programs that take subsidized families assume a loss for every subsidy-paid slot that could have been filled at the full tuition rate of a nonsubsidized family. Finally, states differ in the type of care that subsidy dollars will pay for. Some do not provide child-care subsidy payments to relative caregivers.

Other policy actions that influence rural child care and caregiving to children, legislate the practice of care in regulated facilities and family child-care homes. These regulations vary by state, but in general, focus on the structure (group size, adult to child ratio) of the programs, safety of the environment, and backgrounds and training of the caregivers.

As a result of these varying and in some cases, punitive practices, rural families may suffer. For example, Davis et al. (2007) determined that families in extremely rural areas (fewer than 10,000 people) received child-care subsidies for a shorter period of time than those in metropolitan (population over 50,000) and micropolitan (population between 10,000 and 50,000) areas. The shorter time use of subsidies was believed to be due to differences in policy administration and to the stigma of welfare receipt in the communities studied.

Finally, there are federal and state tax credits available to low-income families to help offset the cost of child care. At the federal level, the nonrefundable Child and Dependent Care Tax Credit covers a portion of child-care costs for children under age 13 when the care is employment related. Forry and Anderson (2006) assess the limitations on this credit that affect low-income families universally.

At the state level, child/dependent care tax provisions are offered by many states, and applied to state income taxes. At least 27 states have this tax provision (National Women's Law, 2006), many with a significant portion of rural areas and low-income families. Usually, states design the child-care-dependent tax credit as a percentage of the Child and Dependent Care Tax Credit.

Summary

In summary, the current state of care for children in rural areas presents a challenging situation for most parents. Research points to the various aspects of care that parents consider related to quality, individual preference, accessibility and cost, amidst the limited options for regulated care in rural areas. Care options are particularly sparse for infants and toddlers and for school-age children. Regulated public and private options that are available, for instance, through Head Start often call for long commutes or are not conveniently placed near home or work. As a result, and by preference, rural families often choose for care to be provided to children within the family system. Educational efforts are in place to help increase the quality of care through training and support to caregivers and professionals. From a policy perspective, federal and state dollars for child care are primarily focused on assistance to families to pay for regulated care and, in most states, to offset the cost of care by relatives and neighbors. Implementation of these policies varies greatly from state to state, in general, limiting rural, low-income families' access to child-care assistance. Many families make due with what is available to them, and what they can afford. The choices are not easy and in most cases either parents or children or caregivers must compromise.

Future Needs in Research, Programs, and Policy

Rural America faces significant challenges in providing a system of child care for young and school-age children that meets learning needs of its users, recognizes the needs of caregivers and child-care professionals, and supports the employment needs of parents. At a minimum, the programs that provide care arrangements and quality education for children, and that address that quality through staff education and program standards mentioned in the previous sections must continue and be strengthened to address the need for quality care. Yet, to fully address the systemic picture of child care in rural areas and address complex factors, future efforts must move in new directions.

Recommended Action in Programs and Policies

Our policies and programs must take a more family-oriented approach to dealing with care, reflecting parents' preferences for the care of their children in balance with their needs for employment and economic stability. And, while federal initiatives push for quality in early care and after-school settings to better support children's school readiness, school success, and social outcomes, we must not lose sight of the quality of care that comes from within the family system. To accomplish both of these goals requires a research agenda that more cogently incorporates family interests, and the contributions of all settings along the care continuum when examining contexts that best support the development of children and youth.

In general, the policy and program needs of rural families for the care of their children both speak to the need for understanding the range of choices facing families. Policies need to support a broader range of family patterns for work (full time, part time, flexible time, nontraditional hours) and ensure financial assistance to pay for care regardless of when or how much families are able to work. In turn, the availability of child-care programs must reflect the various needs of families. Family-support public and social policies must be more comprehensive to address preferences around work and caregiving that allow all families, despite economic resources, to determine the right balance of parental and non-parental care for their children with family financial security.

As presented in this chapter, for most rural families the decisions around work and child care involve a compromise because one or both options are sorely limited and/or affected by the lack of public transportation and distance. Yet, a more complex and realistic picture of the range of work–family–child care arrangements requires listening more closely to parents, primarily mothers, about their actual desires for caregiving and employment. In the United States, decisions regarding the care of children are overwhelmingly viewed, by both women and men, to be the responsibility of the mother, regardless of marital or socioeconomic status

(Uttal, 2002; Walzer, 1997). Also, it is typically mothers who adjust their work schedules to accommodate changing needs regarding children's care (Walzer, 1997). Therefore, attending to rural mothers' interests provides insight into reasons for work and care choices. But it also reveals preferences as well as practicality. McRae (2003) argues that women's work and family choices are the reflection of varying levels of constraint on choices congruent with mothers' preferences.

The importance of considering the parents' preferences for themselves as the caregivers of their children amidst reports of the child-care arrangements they use and their employment patterns is that it provides a fuller picture of the necessary policy directions for rural families. In addition to providing reliable, high-quality non-parental child-care options, public and workplace policies can support parents' preference to be the primary caregiver for their children. Other developed countries have public policies that support parental care during the first 6 months to a year of the child's life (Michel & Mahon, 2002). Perhaps as the United States better understands the intersection between children's developmental needs and mother's employment and family self-sufficiency, the government will better promote policies that allow families flexibility in making choices that meet all members' needs.

Two proposed policy initiatives that would benefit all families (Lombardi, 2003) are to expand the Family Medical Leave Act and to promote At Home Infant Care Programs. If the Family Medical Leave Act were expanded to all families, not just those who work for large companies, rural low-income parents with limited employment options would have job security if they took off time to care for a new child. Admittedly, this might be a risky and expensive venture for small companies (Phillips, 2002) who may be better suited to developing flexible policies independently. In addition, Lombardi proposes that states find creative ways to finance the FMLA to provide monetary supports to families, so that income is secured. The At Home Infant Care program pays parents a subsidy if they choose to stay at home with their infant, rather than place the child with another care provider. A few states are experimenting with this alternative action for subsidizing child care. Considering difficulties of distance to care and employment, and limited public transportation options in rural areas, enhancement of financial assistance to parents to provide at-home care for their children would seem of particular benefit to rural, poor families.

Recommended Education for Caregivers and Early Childhood Educators

Models of education and training that aid in the professional development of child-care professionals in remote areas should build on practices that use distance learning techniques, make connections between isolated caregivers, and feed into state structures of rewarded and articulated movement to obtain higher levels of formal education and program credentialing (Collins & Carlson, 1998).

Future initiatives in education must especially focus on the needs of rural caregivers. Many of the issues and initiatives described in other chapters in this volume may serve as models for agencies seeking to support relative child caregivers. For example, there may be parallels between the health-care system as a context for family caregiving (Harper, Davis, and Gillis, 2011) and the early childhood education system as a context for informal child care in rural areas. State-level supports to caregivers (Greene, Scott, Perkins, and Burt, 2011) may be similarly extended to relative child-care providers, though administered from a different public agency. As Walker et al. (1995) have called for an interface between the professional and informal community in family caregiving, so can this partnership work to support child care.

Recommended Action in Research

Address Cultural Diversity

Future directions for research and practice will also address cultural diversity of families and caregivers and needs of children in rural areas. Decisions around the use of care, models of caregiving and child rearing, communications within the family and intersections with the community, are culturally based (Uttal, 1999). Supports to family members providing child care, and to rural parents in their selection of care from all care types will be more effective when they are sensitive to interests founded within culture, race, and ethnicity. A promising step in this direction is being made by the National Center for Rural Early Childhood Learning Initiatives at Mississippi State University (http://ruralec.msstate.edu/). Several strategic projects that began in 2005 are seeking to uncover gaps in services to native young children and helping native educators develop culturally appropriate early childhood curricula that will foster preservation of native languages and culture.

Consider the Economic Impact of Rural Child Care

Research must uncover the economic impact of child care as it contributes value to social and educational impact on children and families (Paulsell, 2001). Within the family system, child-care provision by relatives fulfills economic interests (Uttal, 1999). Child-care businesses also contribute to the economic sustainability of communities, by maintaining parental employment and contribution of income taxes, by offering employment to child-care workers, and through taxes paid by child-care businesses. An understanding of the scope and place of child care for young children and children in after-school settings as an influence on the economic stability of rural areas can enhance its importance as a public good and can result in a greater investment of public interest and funding. When this occurs, more comprehensive options will be made available to encourage the financial security of rural families and the well-being of children and youth.

Concluding Comments

Future directions for strengthening our support to rural families and their children through child care and caregiving will respect families' choices and preferences. It also will present them with quality options that help children grow and develop. Along with more global research that continues to investigate quality in regulated care, pre-kindergarten, and school readiness, we advocate for research on how family relationships operate and influence a quality experience for care provided within the family system. This type of care is the reality for many rural families. Public policies and resources are needed to develop further the infrastructure of regulated early childhood and school-age care programs for rural children. Transportation to those programs is a necessity. Initiatives to better train teachers are a critical part of the formula. At the same time, future efforts should find ways to strengthen resources within rural families' systems, supporting them as a viable child-care solution.

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Part II
Practice and Research Issues

Chapter 5
Addressing Disparities in Rural Health

Tawanda M. Greer

It is estimated that by the year 2025, the USA' racial and ethnic minority population will have increased to account for at least 40% of the nation (U.S. Department of Health and Human Services, 2001). As the number of racial and ethnic minorities increase in America, so too does the number of adverse physical and mental health conditions among minority populations. A plethora of literature exist which document the disparities in health conditions between Whites and racial and ethnic minorities in the USA (e.g., Myers et al., 2003; Williams & Rucker, 2000), with minority populations experiencing limited access to health care, the most severe health problems, and overall poorer quality of care. Even when racial and ethnic minorities possess health coverage that is comparable to the levels of Whites, research evidence suggests that they still receive poorer quality of care for the same or similar health conditions (Alliance for Health Reform, 2004).

Although federal and some state initiatives are underway to address existing health disparities in the USA, more attention needs to be paid to the unique problems experienced by health-care professionals in rural settings as well as barriers to health care that are in existence for rural populations, especially for rural persons of color. This chapter has two primary objectives: (a) to discuss current issues faced by rural health-care systems and rural Americans, with a particular focus on racial and ethnic minorities in rural settings, and (b) to suggest interventions to effectively address existing problems in the provision of health care in rural settings. General factors contributing to existing health disparities in the USA will be discussed first, leading to the discussion of unique problems faced in rural settings.

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Sociocultural Sources of Health Disparities

A review of the research literature on health disparities points to a myriad of factors that have contributed to differences in experienced health problems between Whites and persons of color in the USA. Although some sources of health disparities are biogenetic in nature, many sources of disparities are not. The following paragraphs will provide a brief discussion of primary sociocultural factors that contribute to health outcomes that vary by race and ethnicity within the USA.

Lack of adequate health-care coverage. The existing literature identifies the lack of affordable health care and being underinsured as primary contributors to health difficulties among persons of color. Cohen (2003) noted that "the issue of lack of insurance is an absolute indictment of our system, with as many as 42 million uninsured Americans, and is our single biggest problem in terms of health care disparities" (p. 1155). Williams & Rucker (2000) suggested that problems with health-care coverage among persons of color are associated with low socioeconomic status, high rates of unemployment, and underrepresentation in jobs that provide health insurance as part of employment packages.

Racism and unfair discriminatory practices. When patients of color are insured at levels comparable to their White counterparts, minority patients still receive inferior quality of care (Alliance for Health Reform, 2004; Harris et al., 1997). These findings point to acts of racism, discrimination, and other forms of biases on the part of health-care professionals. For instance, van Ryn & Burke (2000) found that physicians rated Black patients as less intelligent and undereducated compared to White patients and less likely to comply with recommended treatment for cardiac rehabilitation. Additionally, physicians in this study rated Blacks as more likely to engage in substance abuse, less likely to engage in physically active lifestyles, and to be at high risk for low social support compared to Whites. Racial prejudices and biases among health-care professionals have also been found to be contributors to disparate health-care practices regarding diagnoses, referrals, and various interventions (e.g., analgesic prescription patterns), particularly for ailments such as cancer, cardiovascular diseases, kidney failure, HIV/AIDS, and diabetes (Institute of Medicine, 2003; Sullivan Commission, 2004).

Communication barriers. Many racial and ethnic minorities utilize English as a second language. However, in general, health-care professionals with diverse racial, ethnic, and linguistic backgrounds are not highly represented within medical and mental health professions. Therefore, the chance of problems arising in interpersonal interactions between providers and patients are great. Such problems can potentially lead to misunderstandings on the part of health-care professionals regarding the nature and severity of client/patient symptoms, health history, and the degree to which patients/clients fully understand interventions and provided treatments. Barriers in interpersonal interactions also have been shown to contribute to low patient/client satisfaction with care received, poor follow-ups, and poor adherence to treatment plans, particularly when translators are not available (Alliance for

Health Reform, 2004). For instance, some research evidence has shown that many Spanish-speaking Latinos do not seek needed health care due to language barriers experienced in communicating with health-care providers (Alliance for Health Reform; Anderson et al., 2003).

Managed care and cost-containment. Gatekeeping policies and procedures of managed care have also contributed to existing health disparities. A significant number of Americans' health-care costs are covered by managed care plans (U.S. Department of Health and Human Services, 2001). Managed care plans can be very attractive to purchasers due to their low cost as well as their other purported benefits (e.g., increasing access to care, promoting evidence-based treatments). However, some racial and ethnic minorities feel that managed care poses greater barriers and limits in accessing care when compared to fee for service care (Provan & Carle, 2000). Additionally, managed care often limits access to health-care providers who primarily care for poor, disadvantaged populations (Harvard Law Review, 1995). Many health-care providers generally view patients who are low SES as undesirable (van Ryn & Burke, 2000), as their conditions may require extensive medical attention and consequently leads to higher health-care costs (Williams & Rucker, 2000).

Sociocultural contributors to rural health disparities. In understanding challenges in the provision of health care in rural settings, it is imperative that policy makers and stakeholders appreciate the intersections of race, ethnicity, socioeconomic status, and class as central to many dilemmas faced by rural residents. Racial and ethnic minorities currently comprise nearly 17% of the U.S. rural population, and this number continues to grow (U.S. Department of Agriculture, 2004a). Among rural racial and ethnic minorities, 33% of African Americans, 35% of Native Americans, and 27% of Hispanic Americans account for rural poverty rates, compared to a poverty rate of 11% among rural non-Hispanic Whites (U.S. Department of Agriculture, 2004a). The poverty rate of rural multiracial residents is also higher than that of non-Hispanic Whites at 19.5% (U.S. Department of Agriculture, 2004a). On average, the rural poverty rates among African Americans, Hispanic Americans, and Native Americans are at least 10 percentage points higher than their counterparts residing in urban areas across the USA (U.S. Department of Agriculture, 2004a). The degree of rurality also is related to poverty, especially persistent poverty. The U.S. Department of Agriculture (2004a) reported counties as persistently poor if 20% or more of a county's residents were consistently poor over a span of 30 years. The poorest counties in the Nation are those located in parts of the West and Midwest. The Deep South is home to the most persistently poor residents and the largest population of rural African Americans (National Center for Health Statistics, 2001).

Since the interconnections of race, ethnicity, class, and levels of poverty greatly impacts the health-care needs of rural citizens, addressing rural health disparities requires multilevel and interdisciplinary initiatives. The following sections will discuss unique challenges faced by rural citizens and will provide interventions to address dilemmas and barriers to health care for rural communities in four broad areas: (a) practice, (b) education and training, (c) research, and (d) policy/advocacy.

Practice

Acquiring access to needed health care is a tremendous challenge faced by many rural Americans, particularly rural persons of color. Health-care coverage among rural racial and ethnic minority patients increased between the years of 1990 and 2000 (U.S. Department of Health and Human Services, 2001). However, with the exception of rural Asian American residents, Hispanic Americans, African Americans, and Native Americans are less likely to have insurance coverage compared to their White counterparts. The high poverty rates among these populations increases their likelihood of dependence on social services. Currently, rural African Americans and Hispanic Americans have higher participation rates in Medicaid programs, food stamp programs, and other forms of public assistance than rural White Americans.

In addition to low levels of health-care coverage, rural residents in general have limited access to transportation, especially those located in the most remote, rural counties. At least 1.6 million rural residents do not possess cars, with the majority of "carless" rural citizens residing in areas of the Deep South, Appalachia, Alaska, and Southwestern areas of the nation (U.S. Department of Agriculture, 2005a). The proportions of rural communities with the highest concentration of "carlessness" are those who suffer from persistent poverty, which, as previously mentioned, are largely African Americans, Hispanic Americans, and Native American residents (U.S. Department of Agriculture, 2005a). Those without cars are dependent on public transportation, particularly intercity bus services, to which, in spite of some improvements in efficiency due to the contribution of federal funds in recent years, many rural citizens still do not have sufficient access (U.S. Department of Agriculture, 2005a). Following the September 11, 2001 attack, the intercity bus industry experienced a decrease in regulation, with rural areas largely affected by this change. In spite of cutbacks in funding, the intercity bus service remains the primary mode of transportation for many rural residents. Thus, any additional cutbacks will serve to further immobilize rural residents and will certainly increase physical inaccessibility to health care.

In addition to limitations in transportation, many rural settings are plagued with a shortage of health-care professionals with subspecialties, which greatly limits the quality of services provided to patients. Registered nurses comprise the bulk of the rural health-care workforce (Wakefield, 2005), with approximately 11% of primary care physicians practicing in these settings across the USA (Brooks et al., 2002). A small percentage of rural primary care physicians and nurses are racially, ethnically, and linguistically diverse (National Center for Health Statistics, 2004). With regard to mental health, rural areas are 4.7 times more likely to have lower numbers of mental health providers compared to urban areas in general (Merwin et al., 2003). The limited supply of health-care specialists implies that there is a heavy reliance on generalists in the provision of health-care services to rural patients, which inherently leads to problems in treating complex medical conditions and in effectively addressing issues of comorbidity.

The problems in providing health care to rural patients are exacerbated by the conditions of many facilities themselves. Rural health-care facilities may be old and limited in advanced technology (Hood, 2004). The technological limitations of some facilities, in many cases, prompt the need for transfers to urban facilities for medical services, leading to additional risks for transferred patients (Mantone, 2005). Furthermore, rural health-care facilities are limited in number. Thus, patients contend with limited choices of where to seek care, especially rural racial and ethnic minority patients due to the low availability of clinics and hospitals in non-White neighborhoods.

In sum, residents of rural communities face complex challenges in accessing available health care. The effects of rurality are seen particularly among many rural racial and ethnic minorities in which the limited availability of health-care services and other resources are exacerbated by poverty. Thus, to improve health-care practice in these areas, interventions must center on increasing the health-care workforce in rural communities. Furthermore, interventions should help to ensure that rural patients can connect with existing services within their communities and with available specialist services that are adjacent to or in close proximity to their communities.

Future Directions for Rural Health-Care Practice

Perhaps a primary step in ensuring access to health-care services among rural populations is to address the problems associated with limited transportation. Given the limited access and use of independent modes of transportation (e.g., cars), particularly among racial and ethnic minority residents who are poor, improving the access and quality of public transportation is paramount. Rural partnerships should be developed among administrators in health care, transit operations, and other community leaders for the sole purpose of assessing community transit needs and developing strategic plans to improve transit access.

Grant support at the federal level is available for projects centered on improving public transit operations in rural communities. On August 10, 2005, President Bush signed the Surface Transportation Reauthorization Bill into law, guaranteeing the availability of $45.3 billion in Federal transit programs between the Fiscal Years of 2005 and 2009 (Federal Transit Administration, 2005). The Safe, Accountable, Flexible, Efficient Transportation Equity Act (SAFETEA-LU) legislation allows communities across America to improve access and quality of public transportation among elderly citizens, persons with disabilities, and persons with low incomes (Federal Transit Administration, 2005). A subsection of the SAFETEA-LU legislation is specifically geared toward addressing the transportation needs of rural or nonurbanized areas. Thus, the new legislation provides needed opportunities for improving public transportation in rural areas and, in turn, improving citizens' access to available health-care services, employment, and other needed services.

In addition to increasing transit access, rural health-care staff should seek collaborations with health-care specialists in adjacent or neighboring urban communities.

This would allow for consultation regarding medical conditions that require the skills and expertise of health-care specialists.

Telemedicine is one viable option in increasing contact between health-care professionals in rural and in urban areas. By using videoconferencing and other forms of technology, telemedicine can be beneficial for rural communities in improving health-care practice, especially in the diagnosis and treatment of complex medical cases. The drawback to telemedicine, however, is the high cost of setting up advanced technological systems in rural health-care facilities. As mentioned previously, many rural facilities are old and lack technological capabilities. Furthermore, ongoing technical support would be needed to ensure the quality and performance of these systems. Therefore, it is also recommended that grant support seeks to address challenges in improving health-care technology in rural health-care facilities. For instance, the US Department of Agriculture is one agency in which funding opportunities are available to enhance rural technology through the Distance Learning and Telemedicine Program (DLT) and through the Community Connect Program (U.S. Department of Agriculture, 2005b). These funding programs afford rural health-care partnerships the opportunity to connect to services that will enhance learning and connect to services historically unavailable in many communities. In short, telemedicine can prove to be a useful means of improving the quality of health-care services in rural communities. Additional information regarding telemedicine and its benefits is located later in this volume in the chapter by Yellowlees and colleagues.

An additional goal for rural health care is to increase the number of quality health-care providers, and particularly specialists, in rural areas. Improving transit access and moving toward the use of advanced technology and telemedicine helps to bridge the gaps in this area. However, additional strategies are needed to increase the number of medical practitioners and specialists who provide services within these communities. In many rural communities, few practice incentives exist to attract large numbers of primary care physicians and other medical specialists. Many states have made attempts to address this problem by adopting practice incentive programs for health-care professionals who desire to work with underserved rural populations. Practice incentives generally include federal loan repayment programs, high needs service bonuses, and tax credits, with some states providing incentive tax credits up to $5,000 annually for 5 years of service among eligible rural physicians (Henderson & Lewis, 2000). These types of incentive programs should continue as they help to address the shortage of health-care professionals in rural areas.

Furthermore, the *pipeline strategy* has been used to recruit health-care professionals to rural areas. This strategy exposes young children and adults to medicine and other health-related professions throughout the formal educational process. The goal is to encourage future entrance into the health-care workforce. Several programs have already been implemented in rural communities for students in grades K-12 to increase their exposure to science, health, and various aspects of technology (Institute of Medicine, 2004). Some research evidence supports the long-term effectiveness of the pipeline strategy. For instance, Brooks et al. (2002), in their analysis of slightly over 20 quantitative articles on the recruitment and retention of primary-care physicians in rural areas, discovered that rural upbringing and specialty interest were strongly associated with attracting premedical students to rural practice areas. However, in some of the reviewed studies, premedical school training and curricula that emphasized rural issues were found to be more effective in retaining primary-care physicians than upbringing and specialty interest alone (Brooks et al., 2002). Thus, the pipeline strategy may hold some promise in retaining rural health-care physicians and specialists.

In addition to the pipeline strategy, increases in the rural health-care workforce can be accomplished by engaging in strategic health planning in which health-care systems are viewed as primary agents in improving economy. For many rural communities, the health-care sector is the primary source of employment and economic stability. In some states, health-care systems are responsible for nearly 20% of the economy in rural counties (Doeksen & Schott, 2002). Benefits of a stable rural health-care system, in addition to improved quality and access to care, include the increase in investments of small businesses and the attraction of retirees, which serve to further stabilize rural economy.

Strategic health-care planning is complex and thus should begin with collaboration among community leaders and local health-care professionals. The process of strategic planning should include consideration of the following: (a) local health-care services and limitations in service provision; (b) current makeup and quality of the local health-care workforce and additional workforce needs; (c) socioeconomic conditions of the populations; (d) common medical problems and health-service needs; and (e) the status of local health-care revenue, including an estimate of health-care dollars that flow outside the community versus health-care dollars flowing within the community. As previously noted, there is some research evidence and there are a number of recommendations available to guide efforts in each of these areas. Rural communities should engage in a formal, health-care needs assessment as a first step in strategic health planning. The results of the assessment can be utilized to further community actions such as determining needed federal and state grant support, engaging in feasibility studies, and deriving strategies to recruit and retain health-care specialists. Community leaders and rural health-care professionals should consult with colleagues across states in order to gain ideas and receive feedback on plans and strategies.

The health-care workforce must also be culturally competent. Much work is needed among health-care providers to improve their interpersonal interactions with consumers of health care in both rural and urban areas. All health-care disciplines are governed by a code of ethics, which generally upholds the value of engaging in practice that enhances the overall well-being of populations served. Given the continuous change in the demographics of health-care consumers, health-care systems and providers are challenged to adapt and to devise innovative strategies to meet the needs of various populations while remaining sensitive to cultural context (i.e., cultural competence). Anderson et al. (2003) defined cultural competence in health care as "…a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enables effective work in cross-cultural situations" (p. 68). In spite of the broad goal to increase cultural competence, unfair discriminatory practices that serve to disadvantage patients/clients occur often among health-care providers, especially in their work with racial and ethnic minorities. Some research evidence exists suggesting that some health-care providers are often unaware of their discriminatory practices (Williams & Rucker, 2000). For instance, the Alliance for Health Reform (2004) reported that, on average, 70% of American physicians believe that racial and ethnic minorities are "rarely" or "never" treated unfairly within health-care systems, thus implying an overwhelming commission of unintentional racism and discrimination by health-care providers. Awareness is the first step in addressing racism and unfair discriminatory practices in health care. It is important for health-care providers to acknowledge that chronic forms of racism and discrimination, whether actual or perceived, pose negative impacts on the overall health status and well-being of racial and ethnic minorities in particular (Klonoff et al., 1999; Loo et al., 2001).

Education/Training

One way to improve upon health disparities is to improve educational attainment and economic conditions in rural areas. In recent years, the educational attainment of rural Americans has increased over the years. In the year 2000, an average of one in every six rural adults possessed a 4-year college degree, with younger rural adults significantly more educated than middle-aged and older adults (U.S. Department of Agriculture, 2003). In spite of the rise in educational attainment, many rural Americans still do not have high school diplomas. This trend is seen particularly among racial and ethnic minority populations. In the year 2000 alone, the percent of rural Native Americans, African Americans, and Hispanic Americans without a high school diploma was 31.8%, 39.8%, and 51.6%, respectively (U.S. Department of Agriculture, 2003). Among rural White Americans in 2000, the percent of adults without high school diplomas was 20.2% (U.S. Department of Agriculture, 2003). Low educational attainment is seen among rural Americans who are persistently poor, with areas of the South having high concentrations of rural citizens who have not completed high school (U.S. Department of Agriculture, 2003).

Low educational attainment among significant proportions of rural residents plays an important role in rural economic development. Historically, skill-level requirements among the labor force were not sufficiently high due to the prevalence of jobs that did not require skills beyond physical labor and routine tasks (e.g., farming). Occupations such as construction, agriculture, and manufacturing were once the driving forces of rural economy and largely represented the employment options for many rural residents. After 1990, an industrial and occupational shift occurred in which technology and other industrial changes began to require less of a need for low-skilled rural laborers. Currently, the economy and the rural labor force have shifted from the production of goods to service-oriented occupations, such as communications, and service jobs in local government (U.S. Department of Agriculture, 2004b).

Increases in high-skill service-oriented jobs are positive steps toward economic growth for many rural communities. Improvements in health-care systems through strategic health planning could only serve to further raise the bar regarding high-skill-level jobs and more employment demands for highly educated rural residents. However, shifts in the demand for highly trained and highly skilled workers could lead to marginalization among rural residents who are persistently poor, with low skill levels and low levels of education. Since a significant proportion of those who are persistently poor and with low skill levels are rural Native Americans, African Americans, and Hispanic Americans, these groups will be most adversely affected by such shifts in labor demands. Therefore, improvements in education are needed to improve economic status and access to health care, as jobs with higher skill demands generally include health insurance as part of employment benefits packages.

Future Directions in Rural Education and Training

As rural communities across America begin to engage in strategies to improve health care and economies, it is important that further marginalization does not occur among rural citizens, particularly among persons of color. Improvements in rural educational systems are primary ways to protect residents from becoming disenfranchised from their own communities. In particular, community leaders and educators should collaborate to develop strategic approaches to improve the educational levels citizens who have not completed high school. Additionally, emphasis should be placed on job skills training and other vocational needs in order to ensure that rural residents have better employment opportunities.

Rural communities that lack resources to implement approaches to educational improvements should seek collaborations with other community leaders, in addition to seeking state and Federal funding opportunities. For instance, the Appalachian Regional Commission (ARC) consists of partners at both state and federal levels to improve the economy of rural Appalachian communities and the overall quality of life of Appalachian residents. This partnership alone has made tremendous strides in rural development in several needed areas (e.g., transportation programs), but especially within the areas of education and training. ARC collaborations extend to several states and have led to innovations such as on-line professional development programs for students and teachers in upstate New York, as well as projects to enhance learning through the integration of technology (Appalachian Regional Commission, 2005). Thus, it is strongly recommended that rural communities interested in improving education and training programs begin the process by seeking information about programs and initiatives that have already been implemented. This information can then be used to determine if the implementation of similar programs will meet the needs of communities that have been targeted for change.

Beyond improving the overall education levels and increasing rural residents' education in the health-care professions, rural leaders must also attend to increasing cultural competence among existing professionals. Ongoing diversity training is needed to assist health-care systems and providers in becoming culturally competent in practice. Health-care professionals must challenge their own biases, stereotypes, and prejudices in their work with various populations. Diversity training should not only prepare health-care providers to effectively navigate cross-cultural interactions, but also intra-cultural interactions (Greer, 2005). Health-care professionals who are racially, ethnically, and linguistically similar to patients/clients may hold an advantage in communication due to potentially shared cultural values and societal experiences. However, cultural similarities may also lead to potential "blind spots" on the part of health-care professionals in which severe illnesses and problems may be overlooked, or minimized, also contributing to poor quality of care. Overall, health-care systems should actively engage in a commitment to increase cultural understanding and sensitivity among providers in order to improve the quality of health-care practice with diverse populations.

Research

As previously discussed in the review of sociocultural issues in health disparities, there is some research available on biases in the health-care system and among health professionals (e.g., Alliance for Health Reform, 2004; van Ryn & Burke, 2000). In addition, there has been some research related to innovative health-care delivery models designed to improve health disparities. For example, nine studies were identified that involved randomized controlled trials to evaluate pay-for-performance programs designed to improve the quality and equality of health-care delivery, although the results for such incentive programs have been inconsistent to date (Institute of Medicine, 2004).

Additionally, welfare reform potentially contributes to tremendous disadvantages for segments of rural populations who are persistently poor and who, as previously stated, consist largely of racial and ethnic minorities. According to a recent report by the National Bureau of Economic Research (2003), the numbers of low-income families without health insurance increased during the years following the passing of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) legislation of 1996. This effect is potentially due to limited employment opportunities for those transitioning-off of public assistance, in which low-wage occupations that did not offer private health insurance were available. Currently, little is known about the effects of welfare reform among low-income rural citizens. Thus, research initiatives are greatly needed to understand impacts and the extent to which welfare reform contributes to low health insurance coverage among poor rural Americans.

Great challenges exist in conducting research on rural populations due to many of the unique characteristics of rural residents in comparison to those residing in larger, urban areas of the nation (e.g., socioeconomic conditions, transit limitations, health and other social service needs). In addition, many conditions and needs of different rural communities are not uniform, which presents methodological limitations and limited generalizability of research findings. Even criteria that help to define populations as rural lack uniformity. Departments such as the U.S. Bureau of the Census generate rural definitions, and rural classification systems may vary among departments. Thus, what constitutes a population as "rural" may differ based upon key factors such as population density, various measures of isolation, or degrees of rurality. The lack of a standardized definition of "rural" poses difficulties in accessing needed data from federal and/or state departments, as the choice of a definition dictates the data that is available. Inconsistent definitions further limit comparisons across rural communities. In addition to methodological problems, the health-service needs of rural populations vary. Thus, research to address high-priority health-service needs will differ from one community to another.

Future Directions for Rural Research

In order to begin to effectively address challenges related to health and rural health-care delivery, improvements in research methodology must occur. As previously stated, major problems stem from the lack of a uniform definition of "rural," as well as inconsistent availability of data between state and federal level departments. Thus, to help promote better understanding of outcomes among rural populations, some basic reporting strategies should be incorporated into research. Specifically, researchers should report rural definitions and classification systems for specific areas or populations. Researchers should also report zip codes, counties, and other information that identifies locales in order to enhance understanding of trends and outcomes in specific regions.

Additionally, researchers who conduct studies on national trends and quality-of-life indicators (e.g., health, health care, poverty) should include more description of rural populations. Many large, national studies include sample participants from rural populations; however, few reports from these studies include details regarding experiences and trends seen among residents. Researchers should begin to include these descriptions in order to contribute to understanding of outcomes among rural citizens and also to allow comparisons of results with other research studies.

Research focused on rural populations should begin to integrate multiple methods in study designs. Qualitative methods should be integrated with quantitative approaches to enhance research initiatives. Focus groups and other ethnographic approaches can serve as precursors to quantitative studies, particularly when little information is known about specific phenomena, such as welfare reform effects for rural populations. In general, qualitative approaches can provide depth and richness in description that is not available through the use of survey data and other forms of quantitative approaches. Furthermore, qualitative methods are inherently culturally sensitive and can be used to overcome barriers related to reading ability and language. Overall, integration of multiple research methods will improve the quality of data that are used by community leaders and policy makers in developing initiatives to address challenges in rural health care.

Policy and Advocacy

It is beyond the scope of this chapter to discuss all of the legislation that impacts the state and provision of health care to rural Americans. The impacts of some legislation will vary between communities due to differences in infrastructure and health-service needs. Therefore, this section highlights some region-wide policy and advocacy needs that appear to impact the majority of rural communities, followed by recommendations for continued involvement in policy initiatives and advocacy.

Policies that ensure the quality of health care have undergone significant challenges over the last several years. Perhaps some of the greatest challenges in rural health policy are fluctuations in the priorities of federal government regarding the funding of health-care programs and initiatives. Proposed budget cuts as part of the Fiscal Year 08 budget for the Departments of Labor, Health and Human Services, and Education pose threats to rural health-care programs and initiatives funded through the Health Resources and Services Administration (NRHA, 2007). As part of the proposed cuts, limited or no funding would have occurred for rural health research, health outreach grants, community access program grants (CAP), rural emergency medical services, and rural and community access to emergency devices (NRHA, 2007). In spite of proposed budget limitations, the appropriations bill was opposed and rejected on November 17, 2005 by the U.S. House of Representatives (NRHA, 2007). A current resolution to the HR 3010 bill has extended funding to federal health programs and initiatives through December 17, 2005. However, advocacy is needed to ensure the continued funding of these programs and initiatives.

Additionally, since Congress passed the PRWORA legislation in 1996, various changes in the lives of welfare recipients have occurred, which includes the rural poor. Recent reports on the role of the Temporary Assistance for Needy Families (TANF) program boast significant increases in employment among previous welfare recipients. For example, the nation experienced a 60% decline in TANF recipients between August 1996 and September 2003 (National Advisory Committee on Rural Health and Human Services, 2005). Furthermore, between the years of 1996 and 2001, the USA experienced a decline in child poverty rates, further signifying the success of welfare reform (National Advisory Committee on Rural Health and Human Services, 2005). However, such indicators of the success of welfare reform have not been widely seen among many rural Americans.

The high concentration of areas of persistent poverty, low educational attainment, and problems germane to many rural locations (e.g., limitations in public transportation) pose significant barriers for rural citizens in gaining economic independence. Currently, the reauthorization of TANF has been operating under several temporary extensions due to the lack of agreement within Congress on ways to reauthorize the program. TANF legislation has been extended by the 109th Congress through December 31, 2005 in wake of the impact of Hurricane Katrina on the lives of poor residents of the Gulf Coast (H.R. 3672, 2005). However, future TANF reauthorization could impose additional work requirements, which will greatly impact the lives of many poor residents of rural communities. Opportunities to meet higher work demands as part of TANF will not be possible for a great number of rural citizens due to limitations in employment opportunities. Therefore, many rural residents will not meet work requirements, even when other potential barriers have been addressed (e.g., sufficient child care).

Also, due to economic changes in many communities, as well as characteristics of rural populations previously discussed (e.g., socioeconomic conditions, limited employment opportunities), continued advocacy is needed to ensure that the needs of rural Americans are taken into account in the development of policies in health care. The following are broad areas of policy that greatly impact health and health-care provision within rural communities: (a) public transportation and transit infrastructures, (b) TANF reauthorization and welfare reform, (c) rural health-care workforce and incentive programs, (d) managed care and Medicare reform, (e) rural health research and research grant programs, (f) education grants and graduate medical training programs, and (g) rural economic development. This list of policy areas is by no means exhaustive. Rather, these are priority areas that warrant continued attention on the part of community leaders and health-care professionals. However, little information is available regarding best strategies in addressing these issues through policy development. The work of policy analysts is vital in pinpointing strategies to address these issues at the policy level.

Future Directions in Policy and Advocacy

In order to ensure that the needs of rural citizens are considered in policy decisions, continued involvement in advocacy and other forms of activism is necessary among community leaders and rural health-care professionals. The first step toward legislative involvement is familiarization with current legislation impacting health-care delivery. There are several Web sites and information clearinghouses available through Internet access that serve to keep rural health advocates abreast of changing legislation. For instance, websites of the U.S. Department of Health and Human Services agencies and programs are useful tools for policy information. These generally include, but are not limited to, the Office of Rural Health Policy (http://ruralhealth.hrsa.gov), Health Resources and Services Administration (http://www.hrsa.gov), Administration for Children and Families (http://www.acf.hhs.gov), Centers for Medicare and Medicaid Services (http://www.cms.hhs.gov, and the National Institutes of Health (http://www.nih.gov). Additional agency websites with frequently updated legislative concerns for rural health include the National Rural Health Association (http://capwiz.com/nrha/home/), and the U.S. Department of Agriculture's Economic Research Service (http://www.ers.usda.gov). These sources provide a wealth of information that is useful in gaining awareness about the lives of rural Americans in addition to providing information about current policy issues and initiatives in addressing health care.

It is further recommended that health advocates engage in professional service-related activities that promote the health and well-being of rural Americans. Opportunities for involvement and advocacy are plentiful through state health associations across the nation. For instance, the Rural Assistance Center (RAC) is an agency that is part of the U.S. Department of Health and Human Services. RAC, in collaboration with other federal agencies and programs, functions as a clearinghouse for rural health resources and also as major networking system for community leaders, health-care providers, researchers, policy makers, and all advocates desiring to become involved in rural health-care reform. Thus, the use of resources such as RAC, as well as developing connections with state health associations, will certainly lead to collaborations and partnerships needed to improve the overall quality of health and health care among rural populations. Additional information about RAC and links to each state rural health association can be found at http://www.raconline.org/.

Summary

A number of factors have contributed to existing health disparities within the USA (e.g., lack of insurance coverage, racial and ethnic discrimination). Rural health-care systems, however, are confronted with challenges that emanate from difficulties in national health-care practice, as well as difficulties that are unique to rural populations and rural infrastructures. The current need is for considerable quality improvement initiatives within rural health-care systems. This requires substantial changes within infrastructures to accomplish improvements in effective and efficient health-care practice. Specifically, significant initiatives at federal and state levels are needed to ensure improvements in economy, education, technological advancements, public transportation, health research, and to the recruitment and retention of health-care specialists.

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Chapter 6
Mental Health Concerns for Caregivers in Rural Communities

Martin Morthland and Forrest Scogin

Rural caregivers face unique challenges that affect their mental health. While many attractive aspects of rural-living remain, the fallacy of the "Mayberry myth" has been exposed in the literature. Being a caregiver in a rural locale can mean that the pressures of such responsibilities are compounded by isolation and diminished access to resources. Being a caregiver in a rural area can simply mean, doing more with less. As such, these caregivers deserve particular attention with regard to the mental health concerns they face. The Family Caregiver Alliance (FCA n.d.) defines a caregiver as "anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help." The FCA further specifies formal, or professional, caregivers as, "volunteers or paid care providers associated with a service system," and informal, or family, caregivers as, "[u]npaid individuals, such as family members, friends and neighbors who provide care. These individuals can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately".

When discussing the topic of caregiving (whether rural or urban), there is often an assumption that the care recipient is an older adult. This assumption, although understandable given the prevalence and prominent attention that Alzheimer's dementia caregiving has received, fails to recognize the concerns of diverse populations of caregivers (e.g., rural and urban caregivers of children, adolescents, and younger adults). In fact, a search of the literature on caregiver issues reveals a nearly exclusive focus on the stresses and mental health of caregivers of the elderly and/or persons with dementia in urban settings. There is, however, a small body of research that focuses on the unique mental health issues of rural caregivers across the life span and it is this literature that will be discussed here. Four areas will be reviewed concerning the current status and future directions specific to the mental health

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concerns of rural caregivers: (1) research, (2) practices, (3) education, and (4) policy and advocacy. It is advantageous to think of these four areas as reciprocal in that information from one area may be used to generate activity in another. For example, one can imagine how research may be developed into a practice that is used to educate policy makers. The focus of this chapter concerns informal rural caregivers' mental health concerns. However, much of the discussion can also be related to formal caregivers (e.g., program implementation).

Research

In the United States, there is ample research concerning caregivers as a whole (and even concerning rural caregivers). However, there is a paucity of literature which specifically concerns the *mental health* of *rural* caregivers. There is mental health research that, while not specific to rural caregivers, would appear to be relevant to all caregivers. Although rural and urban caregivers may have many mental health concerns in common, the unique issues faced by rural caregivers may warrant the replication of such studies in rural settings.

To give the reader a sense of the important findings from mental health research for caregivers in general (where replication with rural populations would be of benefit), the following is offered: (1) caregiver distress jeopardizes psychological health (Bookwala et al., 2000; Schulz et al., 1990, 1995; (2) caregivers who are emotionally disturbed are more likely to abuse, neglect, and/or exploit frail seniors (Coyne et al., 1993; Paveza et al., 1992; Pot et al., 1996; Williamson et al., 2001); (3) caregivers who experience undue stress have a higher mortality rate (Schulz & Beach, 1999); (4) chronic stress from caregiving may prematurely age immune responses (Kiecolt-Glaser et al., 2003); (5) quality of care is lower among caregivers who experience anger and/or resentfulness (Williamson & Schaffer); (6) caregiver depression, anxiety, and anger are related to poor physical health of the caregiver, lack of resources, and stressful exogenous life events (Williamson et al., 2001); and, on a more positive note, (7) caregiving may be perceived as a rewarding experience (Cox, 2002; Kramer, 1997).

In 1990, Pearlin, Mullan, Semple, and Skaff developed a conceptually important theoretical model explaining the stress process of informal caregivers (though not specifically rural in focus). This model proposes that issues concerning caregiver background and context relative to primary stressors and secondary role strain and intra-psychic stressors result in mood and cognitive disturbance if not sufficiently mediated by coping or support systems (see Fig. 6.1).

> Pearlin et al. (1990) noted that "[v]irtually everything we are interested in learning about caregiving and its consequences is potentially influenced by key characteristics of the caregiver…[but]we also consider access to and use of resources and programs as important contextual elements of the stress process" (pp. 585, 586). Thus the background and context components of their model have particular relevance to informal rural caregivers. That is, the stress process of informal rural caregivers is likely exacerbated by such factors as lower socioeconomic status and/or working in areas that have fewer formal caregiving support services (e.g., mental health centers) available.

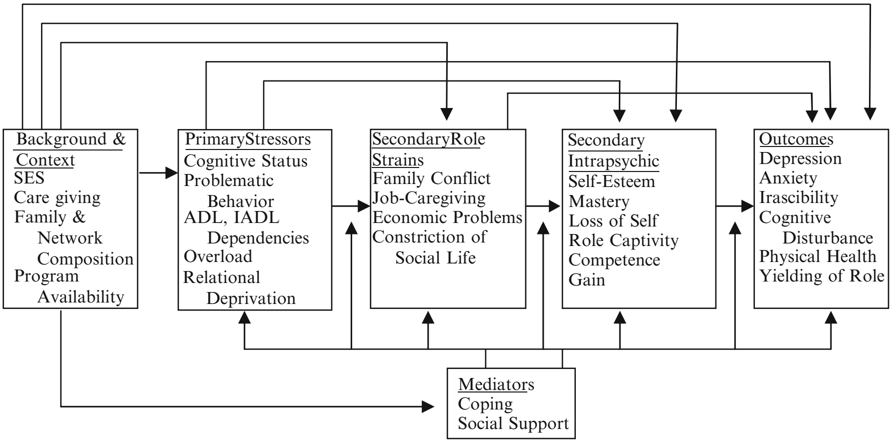

Fig. 6.1 Conceptual model of caregiver stress

The findings of Coward et al. (1994) support this notion. They report that rural seniors have poorer health, rural families have lower incomes, the offspring of rural seniors do not tend to remain in the same geographic location leaving them isolated from extended family support, and formal caregiving services are scarce; particularly those that would lessen caregivers' burdens (e.g., home health, respite care, Meals-on-Wheels, adult day services, mental health case management).

In a study comparing the mental health concerns of rural versus urban caregivers, Dwyer & Miller (1990) used previously collected data from the 1982 National Long-Term Care Survey (LTC) and the National Survey of Informal Caregivers (ICS; U.S. Department of Health and Human Services, 1984). In combining the data from the LTC sample ($N=6{,}393$) and the ICS sample ($N=1{,}924$), older adult participants and their "primary caregivers" were matched across databases to yield a sample of 1,388 rural, small-city and urban care recipients and caregivers (rural $n=283$, small city $n=536$, urban $n=569$). Results showed three important demographic, as well as contextual, differences between the samples that potentially impact the mental health of caregivers. First, rural caregivers had significantly less mean income than those in small cities and urban caregivers. Second, caregivers in rural areas were more often a spouse than was the case with urban caregivers. Third, rural caregivers reported significantly poorer subjective health than both small-city caregivers and urban caregivers. This last finding is important in that subjective health has been found to be a strong correlate of mental health (Pinquart, 2001).

Stress and *burden* are terms that are often used when discussing the mental health of caregivers and are particularly salient when considering the mental health of rural caregivers. Conceptually, these constructs are different. Walker & Walker (1988) define stress as the caregiver's individual reaction to the demands of being a caregiver. Burden, however, is defined by issues such as role-overload, disruption of daily routine, embarrassment, and financial and health deterioration (Poulshock & Deimling, 1984).

Dwyer and Miller's, 1990 study also tested a conceptual model in which rural, small-city, and urban caregivers' stress and burden were related to care recipients' impairments in activities of daily living (ADL) and instrumental activities of daily living (IADL), hours of care needed, and number of paid and unpaid helpers used. Interestingly, given the theoretical distinction between stress and burden, there was only one variable that predicted stress and burden separately (the number of urban unpaid helpers was negatively related to burden). However, in all samples, both stress and burden levels were significantly predicted by hours of care reported by the caregiver and impairments in IADLs.

It is important to note that the rural caregivers received significantly more informal help, in the form of visiting relatives, than in either the small-city or urban samples. In the rural sample only, the number of unpaid helpers was positively related to the number of hours of care reported by the caregiver. In other words, the need for help was recognized and acted upon by informal helpers when the job of the caregiver was greater. For rural caregivers, such informal networks may serve as more important resources than in small cities or urban areas.

More recently, depression among informal rural hospice caregivers ($n=30$) was examined (Ladner & Cuellar, 2002). Depression was measured using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). Approximately 40% of the caregivers were found to be depressed with five (16.6%) in the "severely depressed" category. In an attempt to explain the findings, the authors looked for sociodemographic variables that were significantly related to the caregivers' depression scores. Results comparing ethnicity showed that Caucasian caregivers had significantly higher depression scores than African American caregivers. This result supports other literature that suggests that coping with depression differs by culture (Miller et al., 2000); African-Americans generally have larger support systems and rely more heavily on spirituality. These findings suggest that rural caregivers experience high levels of depression. Moreover, ethnicity may play a part in the prevalence of mood disorders among rural caregivers.

Mental health studies of rural caregivers of non-elderly adult populations are scarce. One such study was conducted by Gammon (2000) who examined the levels of perceived stress and coping strategies used by rural, informal caregivers. A total of 40 caregivers of mentally retarded or developmentally disabled (MR/DD) adults were recruited from rural, southern Illinois. They were administered in-home interviews that measured stress using the Perceived Stress Scale (PSS; Cohen et al., 1983) and the caregivers' styles of coping using the Family Crisis-Oriented Personal Evaluation Scale (F-COPES; McCubbin et al., 1987).

The results mirrored the broader literature by showing that most caregivers were female ($n=31$), married ($n=24$), and parents of the MR/DD adult ($n=36$). The caregivers included 28 Caucasians, 11 African-Americans, and 1 Hispanic.

Results on the PSS were compared with the general population norms established in the instrument's development (Cohen et al., 1983). The results showed that for these rural caregivers, perceived stress was significantly higher among both sexes and across the three ethnicities. Furthermore, African-Americans reported significantly higher levels of stress than Caucasians. In the previously described study by Ladner and Cuellar, the African-American caregivers were less depressed than the Caucasian caregivers. This suggests that while depression may be lower among African-American caregivers, their levels of perceived stress may remain high.

Results on the F-COPES were also compared with the general population norms established in the instrument's development (McCubbin et al., 1987). Results showed that female rural caregivers reframed stressful events (e.g., accepting that difficulties occur unexpectedly) to make them more manageable, compared to the normative sample. Yet both males and females in this sample sought significantly more spiritual support than the normative sample, and also mobilized family members for help significantly more often. When ethnicity was examined, the only significant difference between this sample and the normative sample occurred on the passive appraisal subscale which measures avoidance responses due to the perception that the outcome cannot be altered by the individual. The African-American/Hispanic sample used significantly more passive coping strategies than the Caucasian sample. This may stem from a sense of disenfranchisement with the service system, or as Ladner and Cuellar (2002) suggest, a different coping style as a function of culture.

Overall, the study by Gammon (2000) suggested that these rural caregivers of MR/DD adults experienced more perceived stress than the norm. While the relation between caregiving and stress is intuitive, these results elucidate the fallacy of the "Mayberry myth" mentioned earlier as rural caregivers experience high levels of stress. Furthermore, the author emphasizes that the treatments available to these caregivers such as behavioral-management services and respite care is often limited as a function of their rural environment. With regard to coping strategies, females tended to reframe stressful events, both sexes of this sample sought more spiritual support and mobilized the family to get help and, passive coping was used more often by the African-American sample than the Caucasian. An important question is whether these coping strategies may mediate the rural caregivers' primary stressors, secondary strains, intra-psychic factors, and mood and cognitive disturbance outcomes as proposed by the conceptual model of caregiver stress (Pearlin et al., 1990).

Stress was also the topic of a study examining the effects of respite care (conceptualized as formal social support in this study) on a rural sample of caregivers of developmentally disabled children (Cowen & Reed, 2002). The researchers recruited caregivers from 148 families in a "rural Midwestern state." Stress was measured using the Parenting Stress Index (PSI; Abidin, 1990). The PSI measures stress on different subscales associated with the child's characteristics, the parent's characteristics, and life stress events.

Before respite care, these rural caregivers reported stress levels in the "high stress" range on the total PSI. This overall stress score was driven by stress the caregivers associated with the characteristics of their children (adaptability, acceptability, demandingness, mood, and distractibility). An interesting result concerned the mother's self-reported health. Mother's health was the only variable (pre-respite) that was significantly related to both the total PSI and each of its subscales. That is, the poorer the mother reported her health to be, the higher the stress scores were on the subscales and the total PSI. Following respite care provided by community agencies, PSI scores on all scales decreased significantly.

The study revealed a number of important findings regarding rural caregivers (in this case, of developmentally disabled children). First, total stress was inversely related to social support and the mother's health. In addition, parental stress (of which depression is a component) was inversely related to social support, the mother's health, the mother's age, and the father's education. Third, the parent's perception of the child's adaptability, acceptability, demandingness, mood, and distractibility was inversely related to social support and the mother's health. Lastly, stress from external sources was inversely related to the mother's health and, in this study, age.

As was the case with "coping," the conceptual model of caregiver stress (Pearlin et al., 1990) suggests that social support (in this case, respite care) may act as an important mediator within the caregiver stress model, and that this may be important in lowering stress. This is particularly true when the parent is younger, has lower education, is in poor health, and is experiencing external stress independent of caregiving.

Summary

The studies described above represent current research in which the mental health of rural caregivers has been examined. Three themes emerge from these findings. First, demographics (e.g., sex, ethnicity, income, and education) are important variables in relation to the mental health of the rural caregiver: (a) there are fewer resources and lower individual incomes in rural areas, (b) most often the caregiver is a female spouse (or parent), and (c) racial differences may exist in rural areas (albeit based on small samples) where Caucasians experience higher rates of depression and African-Americans use more passive coping skills while experiencing high levels of stress. Second, stress, burden, and depression are commonly used outcome measures in rural caregiver research. These mental health factors are higher within rural caregiver samples than in their urban counterparts. Third, social support and coping are important mediators in the stress process.

Future Directions

More research examining the mental health of rural caregivers is needed in order to develop better practices and policies. Well-established theoretical models exist for explaining the mental health concerns of caregivers but these models need to be empirically tested for relevance and adequacy in rural populations. That is, research conducted to date on the mental health of caregivers needs to be replicated in rural settings to assess the robustness of findings on geographically diverse populations.

In addition, the diversity of caregivers' mental health concerns needs to be more fully developed in the literature. A starting point would be to work within a theoretical model that posits basic demographics as an impetus for such differences, for example, age, ethnicity, sex and rural/urban location of the caregiver/care recipient dyad.

While outcome variables such as stress and burden are useful areas to study in that they are implicitly linked with caregiving, more precisely defined mental health issues of rural caregivers need examination. For example, established diagnostic criteria (i.e., DSM IV-TR; American Psychiatric Association, 2000) for depression, anxiety, and sleep disorders could be measured as distinct outcome variables in rural caregiver research. In addition, longitudinal studies are needed to evaluate outcomes both pre- and post-caregiving. Longitudinal analyses would allow the exploration of causality between stress, burden, and depression as a function of becoming a caregiver to be more precise; rather than as correlational relations.

Finally, the issue of measurement must be addressed. Researchers have noted that there is a question of cultural relevance for many of the instruments used to measure stress, burden, and depression on diverse populations such as minority rural caregivers (Dilworth-Anderson et al., 2002). Studies focusing on the mental health of rural caregivers must carefully scrutinize the psychometric properties of measures used with diverse populations.

Practice

Mental health services for rural caregivers are operating under less than ideal circumstances. Issues of geographic barriers, lack of resources, poverty, poor infrastructure, poor insurance coverage, cultural barriers, and perceived stigma have been noted by several authors (Buckwalter et al., 1991; Kaufman et al., in press; Krout, 1998; Lawrence & McCulloch, 2001; Rathbone-McCuan, 2001; Scheidt, 1985). Furthermore, mental health services are typically implemented in what has been referred to as *de facto systems* (Fox et al., 1995). In other words, these systems are an amalgamation of different mental health providers, medical providers, clergy, nursing facilities, social workers, etc.; all trying to serve the mental health needs of rural areas.

As a result of these challenges, unique rural mental health practices and interventions have been developed. A particularly popular innovation has been to take service(s) to the rural caregiver, which is done primarily in three ways: (1) to individual caregivers in the home, (2) as outreach programs to the community, or more recently (3) through telehealth networks.

Incorporating all three delivery methods is the National Family Caregiver Support Program (NFCSP). The NFCSP was established in 2000 through an amendment to The Older Americans Act (Public Law 106–501) and developed by the Administration on Aging (AoA). The NFCSP is funded through congressional appropriations allocated to individual states for Family Caregiver Support Programs. As explained on the NFCSP website:

> The program calls for all states, working in partnership with local area agencies on aging and faith and community service providers and tribes to offer five direct services that best meet the range of caregivers' needs, including: 1) information, 2) assistance, 3) individual counseling, organization of support groups, and caregiver training, 4) respite care and, 5) supplemental services (2006).

Programs funded by the NFCSP offer a variety of services that support family caregivers. As described below, these services are available to family caregivers of seniors and seniors who care for family members 18 years of age and younger.

Thus, the focal point for many of these projects is not only caregivers of seniors, but also of children (e.g., Caregivers in Crisis/Caregiver Assistance Network, The Arc Project, The Center for Social Gerontology Caregiver Mediation Project, National Center on Grandparents and Other Relatives Raising Children). Many of the NFCSP-sponsored services include "goals and objectives" that focus on the mental health of rural caregivers. See http://www.aoa.gov/prof/aoaprog/caregiver/carefam/carefam.asp for a comprehensive review of caregiver practices throughout the country.

In-Home Delivery

A seminal overview of programs for rural caregivers of older adults was written by Buckwalter & Davis (2002) in an issue brief to the National Family Caregiver Support Program. In this brief, a variety of rural caregiver programs with mental health applications were discussed.

One particularly relevant in-home program was a multisite study that employed a dementia-caregiver training intervention that used the Progressively Lowered Stress Threshold (PLST) model (Buckwalter et al., 1992). The intervention provided dementia education to family caregivers and taught behavior management skills. The results from this experimental study showed that caregivers who "[r] eceived the in-home training intervention felt better about their situation, had more satisfaction with the caregiving experience, an increased sense of mastery, as well as decreased levels of burden, uncertainty and depression" (p. 15).

Another in-home program relevant to the mental health of rural caregivers is The Family Caregiver Support Program (provided by Elder Services, Inc., Iowa City, Iowa). This ongoing program consists of two parts: information and assistance (provides state and local caregiver resources), and family caregiver counseling. The latter incorporates a specialist who provides counseling and mediation, education in caregiving skills, and coordination with community services and resources.

Presently, research funded by the National Institute on Aging (Project to Enhance Aged Rural Living; PEARL; Scogin et al., 2004) seeks to improve the mental health of rural elders and their caregivers through specific interventions. This project uses a randomized-control design (immediate vs. delayed treatment) employing Cognitive-Behavioral Therapy (CBT) to improve quality of life and lower psychological distress. Other variables of interest include social support, quality of the relationship between the caregiver and the care recipient, and stress and burden. The CBT is delivered in-home to elders and their caregivers. Caregivers are taught techniques to facilitate the therapy for elders and to also independently improve their own lives. The caregiver/care recipient relations that the PEARL project is investigating are theoretically driven by an adaptation of the Pearlin et al. (1990) model

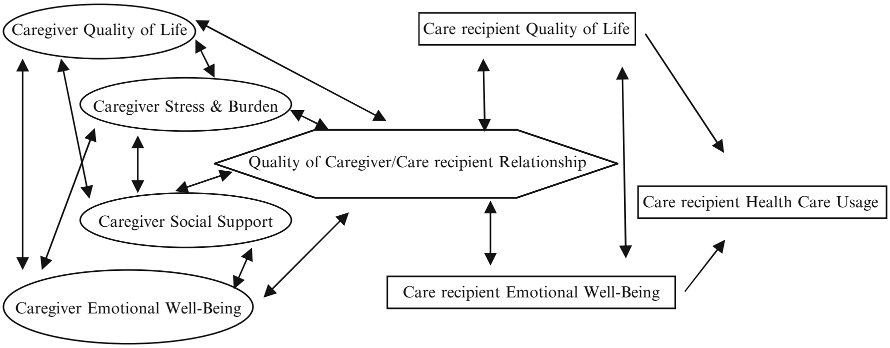

Fig. 6.2 PEARL project caregiver–care recipient interaction model

(see Fig. 6.2) discussed earlier. Formal analyses of the data have not yet been finalized, but preliminary results indicate that, following CBT, perceived quality of life is higher and level of psychological distress is lower for the caregiver.

Outreach Delivery

Outreach programs and models have frequently been used in addressing the mental health concerns of rural caregivers with apparent success. Buckwalter and Davis (2002, p. 12), note that programs in rural Iowa (Iowa's Elderly Outreach Program, EOP) and Virginia (Rural Elder Outreach Program, REOP) have been shown to be, "[e]ffective (as well as cost-effective) in delivering services to geographically and socially isolated elders and their caregivers" (Abraham et al., 1993; Buckwalter et al., 1991; Smith & Buckwalter, 1999). These programs linked the resources of local Area Agencies on Aging (AAA) with community mental health system providers. As discussed in the latter section on Policy and Advocacy, the linking of services to the AAAs is one of the most effective methods of providing mental health services to rural caregivers. The coordination of agencies and systems is key to providing a "seamless delivery system." Incorporating elements of the practices Buckwalter and Davis discussed above, a useful model was developed for successful planning of rural caregiver assistance programs (see chapter by Buckwalter and Davis for an explanation of the R.U.R.A.L. model).

Telehealth

Telehealth is defined as, "[t]he use of telecommunications and computer technologies to make a broad spectrum of health-related services and information available to populations with limited access" (Grigsby & Goetz, 2004, p. 237).

Telehealth has been gaining prominence since the early 1990s. It is seen as a way to increase access for isolated rural individuals and to reduce rural health disparities (Grigsby & Goetz, 2004).

The 1998 *Report on U.S. Telemedicine Activity* noted that the provision of mental health services via teleconsultations made it, "by far the most active clinical specialty in telemedicine" (Grigsby & Goetz 2004, p. 240). Telehealth practices exist across the USA and internationally. Recognizing the national utility of telehealth, the Health Resources and Services Administration (HRSA) established the Office for Advancement of Telehealth (OAT). OAT provides a wealth of information for telehealth practices in both urban and rural localities through its Telehealth Network Grant Program (see http://telehealth.hrsa.gov/).

One telehealth resource relevant to rural caregivers is the Telemedicine Information Exchange (TIE; http://tie.telemed.org/). This organization lists an abundance of telehealth practices that cover mental health concerns of rural caregivers (181 programs at this writing). Programs include both corporate and academically based practices.

One example of a current telehealth practice is the Alzheimer's Early Recognition Telephone System (ALERTS). Located in Wisconsin, it is a telephone-based system that provides information on Alzheimer's disease and other dementias for patients and caregivers. As noted by the TIE Programs Database (2006), "ALERTS offers information on care strategies, tips on dealing with some of the most common challenges, what to expect as the disease progresses, and the importance of self care. Separate assessment tools allow caregivers to monitor their levels of stress and depression".

An example of an academically based telehealth practice is the SIU Rural Caregiver Telehealth Intervention Trial (Chwalisz & Dollinger, 2002). Covering 13 of Illinois' southernmost counties, this project focuses on providing a telephone-based service for caregivers of seniors. The service provides caregivers with "[i] nformation, resources and services, some strategies for approaching and solving care-giving problems, some tips on how to stay connected and get help and support from others, and help them learn how to manage the emotional ups-and-downs" (Chwalisz, 2003, paragraph 10).

Future Directions

Practices that provide mental health services to rural caregivers must incorporate a number of key strategies. First, the design and pursuit of funding for programs must be accomplished by individuals who see the implementation of a project as a permanent fixture of the greater rural health-care system. The importance of such individuals as "social entrepreneurs" has been supported in the literature (Buckwalter & Davis, 2002; Dobkin, 2001). These individuals can come from the community, the service-sector, or academia. In other words, the permanence and effectiveness of the programs is dependent on effective management.

Future mental health practices must be based on models with empirical support of their efficacy, while also being mindful of the unique aspects of local rural-community needs. This in turn should benefit the process of requesting and acquiring funds; the pursuers of which need to understand the organization of granting-agencies and how to structure the request.

Coordination among programs and agencies is essential for developing and maintaining a successful rural mental health program. This must be done at both the individual practice level and at state and national levels. Once in place, a steady stream of advertising and recruitment needs to follow. Recruitment may even include "educating" local care professionals as to the need for and efficacy of mental health services for rural seniors and their caregivers, for example, making educational/recruitment presentations to rural senior centers, churches, and county health departments.

Education and Training

In asking to whom education and training should be directed, four groups emerge: rural caregivers themselves, rural communities, rural health providers (e.g., physicians), and policy makers. Rural caregivers need to know that having mental health concerns is part of being a caregiver and to understand that being in a rural locale may present unique challenges. Rural communities need to know that caregivers may be experiencing stress, burden, and depression; and, that such concerns do not justify stigma resulting in increased isolation. Rural health providers need to understand the diagnostic criteria and evidence-based treatments for mental health problems that the caregivers may be exhibiting. Finally, policy makers need to be educated as to the compelling need for funding research, practices, and educational initiatives to address the mental health concerns of rural caregivers. It is important to realize that the education and training of each of these groups can and should occur reciprocally. Equitably addressing the mental health concerns of rural caregivers at each level constitutes the greatest likelihood for confronting mental health concerns across different domains of focus.

An important source of innovation and practice in such education is the Rosalynn Carter Institute for Caregiving (RCI). Established in 1987, the RCI is involved in research, practice, education, and policy initiatives for rural caregivers and their mental health concerns. Since resources for the education and training of rural caregivers' are rare, the RCI is a particularly valuable asset in this regard. Specifically, the RCI has provided caregiver education and training services nationwide via workshops such as *Caring and Competent Caregivers: Professionals Helping Families* and the *Caring for You, Caring for Me: Leader Preparation Workshops*.

Rural caregiver education about the care recipient's mental and medical condition has a reciprocal effect on the mental health of the caregiver. This important content, as discussed by Stoller & Lee (1994), "[c]an relieve anxiety about what to expect, a concern that becomes especially relevant during the final stages of life. To maximize the effectiveness of such an approach, we need to explore innovative methods for implementing educational programs in rural areas" (p. 60).

Educating and training rural communities also has the potential to have a positive effect on the mental health of caregivers by increasing their knowledge of health-care issues and confidence in giving care to the care recipient (Connell et al., 2002). Such community education is difficult but can be achieved through the use of media and encouraging rural health providers (e.g., social workers, physicians, home health-care nurses) to stress the importance of mental health concerns of rural caregivers to their clientele. A more formal approach may be to utilize outreach programs that are designed to educate communities such as the National Association of Mental Health Outreach Partners program (see http://www.nimh.nih.gov/outreach/partners).

A particular concern relevant to the education of communities is the stigma traditionally associated with mental illness, disease, and disability and the negative effect this can have on the rural caregiver's mental health. This process is illustrated in McGinn's (1996) discussion of the issue of rural community stigma on caregivers of adult children with HIV/AIDS. McGinn expresses the relationship between this particularly strong stigma and a lack of community education as follows: "Such negative reactions toward seropositive persons are evident in rural environments as a result of lack of HIV/AIDS information and education and may in fact be stronger than negative reactions displayed in urban areas" (p. 272). McGinn further states, "Although community support in health care is a positive characteristic of rural communities, accessing this support often depends on the individual's ability to meet the community caregiving values" (p. 274).

Rural health providers (e.g., nurses and physicians) can also benefit from educational and training information. Research documents that the first point of contact by rural caregivers for help with mental health issues is typically the primary care physician (Cotton et al., 2004). In light of this, it is paramount that rural health providers have the ability (training) to identify and treat the mental health issues of rural caregivers, and/or make appropriate referrals. As Gale & Deprez (2003) explain, the general medical or primary care sector in rural locales, "[should] render a full range of health services, including but not limited to mental health services. Unfortunately, these providers often do not have the training to recognize early warning signals" (p. 100). Education and training of rural service providers to identify caregivers as at-risk for experiencing mental health problems is, therefore, especially important as these providers are at the front lines for identifying rural caregivers who need mental health services. Ideally, the best solution is to have mental health specialists who are trained and available to operate in rural locales.

The issue of specialty training and education of rural health providers is a topic of concern identified by the Center for Mental Health Services. The Center formed a workgroup (the Rural Mental Health Provider Work Group) to examine the inadequate number of specialist mental health providers in rural areas. The group made

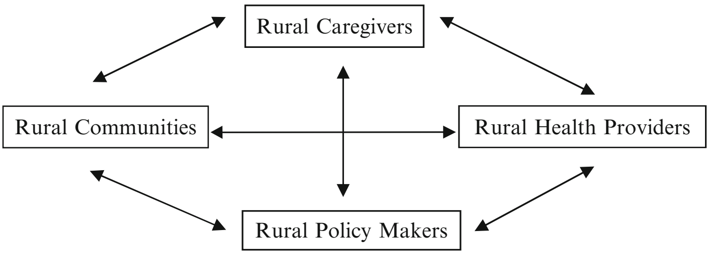

Fig. 6.3 Education and training model for mental health concerns of rural caregivers

several recommendations and stressed the need for mental health professionals to specifically be trained to practice in rural settings, and the incorporation of mental health services within standard primary care.

Lastly, the education and training of policy makers is important for implementing mental health care programs for rural caregivers. Advocacy groups and research grants have contributed greatly to such educational efforts and, consequently, have enhanced the continuance of governmental support to existing rural programs. Advocacy groups provide a voice for rural communities that often use governmental mechanisms for contacting/advocating policy makers when changes are needed in remote communities. Research grants, such as those funded by the HRSA Policy-Oriented Rural Health Services Research Grant Program, have elicited governmental support by identifying rural needs, empirically demonstrating effective methods for addressing those needs, and educating policy makers about the benefit of funding such research (see http://ruralhealth.hrsa.gov/policy/policygrants.htm).

As a result of beneficial policy research/education, the U.S. Department of Health and Human Services established The New Freedom Initiative Caregiver Support Workgroup. This workgroup published a prospectus describing ten governmental organizations and how they directly assist caregivers of all age groups. The workgroup was designed to enhance HHS support of family caregivers of people with disabilities of all ages. “The workgroup plays a leadership role in promoting these solutions as well as coordinating overall HHS caregiver support activities” (HHS New Freedom Initiative Caregiver Support Workgroup, 2003, p. 2).

Future Directions

Rural communities, rural health providers, and policy makers need to progress in the areas of education and training, both independently and jointly. Figure 6.3 depicts a model of rural education and training. This model suggests an interactive and reciprocal process for better serving the mental health needs of rural caregivers.

Policy and Advocacy

It is helpful to understand the hierarchy of the diverse governmental organizations through which policies are advocated and directly funded to better appreciate policy regarding the mental health concerns of rural caregivers. A useful website that illustrates this hierarchy is http://www.hhs.gov/about/org7.jpg. The hierarchy begins at the national level with the U.S. Department of Health and Human Services (HHS). Under the HHS come a number of administrations, agencies, services, centers, and institutes that provide policy and funding.

At the state level, rural caregiver policy is in effect made by the state legislature. However, depending on the state, there may be separate internal departments within which policy may be generated (e.g., Alabama's Office of Primary Care and Rural Health Development). A report by the National Center for Caregiving at the Family Caregiver Alliance, *The State of the States in Family Caregiver Support: A 50-State Study* (2004), notes three findings of importance to rural caregiver policy:

1. Most caregiver support is administered at the state level by State Units on Aging and is available statewide.
2. Area Agencies on Aging (AAAs) are the most common agency to have administrative responsibility for local programs providing caregiver support.
3. In the 15 states (surveyed), all respondents agree that the state should have a single entry point (SEP) for consumers, providing better access to all HCBS [Home and Community-Based Services] programs. In 11 of these states, the SEP includes access to caregiver support (p. vii).

In the 2004 FCA report, state agencies reported the top unmet needs of caregivers. Approximately half of the respondents rated the lack of resources (e.g., mental health services) as paramount. With regard to service-implementation challenges, the respondents noted a "[l]ack of public awareness about caregiver issues and programs, shortage of workers to provide help to caregivers, and access to services in *rural* areas" (p. 41).

Regarding future policy implementation, respondents to the NFCA survey were asked to make recommendations to other states considering the development of caregiver programs. Respondents suggested that they "[e]nsure innovative programs and a flexible array of caregiver support services to meet the diverse needs of families and the individuals for whom they care" (p. 44). Examples of such programs and services were innovative technology, on-line support groups, and mobile respite in rural areas. As discussed earlier, such technology-based policy is currently being implemented, and would likely benefit future mental health of rural caregivers. Policies that invest in technology (e.g., rural telehealth) were among the five issues suggested by the NFCA survey to improve national caregiver support systems. State respondents "[w]ere particularly interested in programs designed to provide a broader array of services, develop consumer direction to maximize flexibility and choice for families, and to use technology with those caregivers who may be difficult to reach (e.g., rural, working, and long-distance caregivers)" (p. 49).

A prolific organization which strongly advocates for mental health policies specific to rural caregivers (among others) is the Rosalynn Carter Institute for Caregiving. Within this organization, there is the National Quality Caregiving Coalition (NQCC), a coalition of national organizations concerned with caregiving, which was founded by former First Lady Rosalynn Carter in 1990. The RCI provides a wealth of resources for the mental health policies of rural caregivers. Indeed, within its mission is a commitment to the promotion of mental health among caregivers, the dissemination of effective caregiving practices, and the delivery of caregiver policy and advocacy.

Future Directions

The future of policies that address mental health concerns of rural caregivers depends on advocacy from rural caregivers and communities, as well as from state and national organizations. A cross-pollination of advocacy must occur for the expedient implementation of rural caregivers' mental health policy. This depends on the starting point of the governing body. Advocacy efforts to governing bodies that affect *caregiving* should emphasize *rural mental health* policy. Similarly, advocating to governing bodies that affect *rural communities* should target *the mental health of caregivers*. Finally, advocating to governing bodies that affect *mental health* needs should focus on the needs of *rural caregivers.* Such methods of advocacy begin at the level of specialty the governing body is chartered to address. Advocacy for specific focus is then made for the additional missing areas in order to fully address the issue of mental health concerns of rural caregivers.

Conclusions

Research suggests that rural informal or family caregivers experience unique mental health challenges given the added burden of limited resources and inaccessibility to services that might improve their quality of life and that of the person(s) for whom they care. Policy makers and providers cannot ignore this segment of our population that we know to be at-risk for mental health problems, particularly when these individuals are often the sole providers of such an important service; one which the majority of us may one day need. When examining the current and future state of mental health for caregivers in rural communities, research, practice, education and training, and policy and advocacy are interrelated and form critical building blocks for fully understanding and addressing the concerns of both family and professional rural caregivers. We need to use research-based evidence to educate and train our caregivers, communities, and policy makers, not only because of the potential benefit that such education can intrinsically have, but also to stimulate policy to actually bring mental health practices to our rural communities. Existing and emerging evidence-based practices for caregivers delivered via innovative means are reasons to remain optimistic about the future of rural caregiving. This optimism must be sustained through advocacy and policy that direct attention to this courageous, yet often hidden group of rural caregivers.

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Chapter 7
Research on Rural Caregiving

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Caregiving in older adulthood has become an increasingly popular research area in the field of gerontology. In the United States, informal (i.e., unpaid) caregivers of older persons provide an average of 26 h a week of care to friends or family, a statistic that has not changed over the past decade. During this same period of time, the number of informal caregivers in the United States has increased from 3.2 to 3.4 million (Center on an Aging Society, 2005). Using the keyword search term "family caregivers," there have been over 10,000 articles added to the National Library of Medicine's PubMed database since 1990. Despite this sizeable area of inquiry, only a small effort has been made to fully understand the caregiving experience in the rural context.

Thus, the purpose of this chapter is to provide an overview of the current state of research in rural caregiving. This chapter is broken down into four sections. The first section addresses what is known. Here, research on aspects of rural caregiving is reviewed and discussed. Second, we provide an overview of conceptual and methodological issues which are relevant to research on rural caregiving. Next, we present a discussion of potential barriers to conducting research in rural communities and the importance of community-based participatory research. To conclude, the chapter focuses on what is needed with respect to future research on rural caregiving.

What is Known

We have reviewed original research on rural caregiving to assess how rural residence influences caregiving. We used a narrative approach in this literature review rather than a meta-analytic approach because it allowed for inclusion of a wide

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range of studies that used different methodologies. Also, a narrative approach was logical given the relatively limited body of rural caregiving research. To find articles, we conducted a search of six well-known databases, including Alt Health Watch, CINAHL, Health Source, Medline, PsycArticles, and PsycINFO. Search terms included rural, nonmetropolitan, family caregivers, family caregiving, informal caregiving, and informal long-term care. The search was limited to original research articles published between 1990 and 2007 on informal caregiving of rural older adults in North America. All of the articles had to be available in English and published in peer-reviewed refereed professional journals. We also used reference lists from identified articles as a way to augment our database searches.

The majority of these studies had a clear and well-documented focus on some aspect of rural caregiving. In some cases, however, the research did not explicitly cite the influence of the rural environment on caregiving as its main objective (i.e., residence was only one of several variables and was often used as a covariate). These multivariate studies were also included in our review and carefully examined to determine whether the authors reported the association between rural residence and the outcome of interest.

The three authors of this review conducted separate literature searches to ensure all relevant studies were considered. We independently reviewed these studies and then came to an agreement on which ones met our inclusion criteria. To organize the research, we then extracted data summarizing the key study findings from each article. We independently reviewed the studies and categorized them as either rural/urban comparative or rural-only studies, classified the research methods as quantitative, qualitative, or a combination of both, either cross-sectional or longitudinal, noted whether it was an intervention study, and identified whether the research was based on a probability or a nonprobability sample. Finally, we independently identified prevalent methodological shortcomings and met to synthesize the literature and develop our discussion of these issues.

Table 7.1 summarizes the 31 studies that met our inclusion criteria. Of these studies, 11 were rural/urban comparative studies and 20 were rural-only studies. Overall, 22 studies were quantitative, seven were qualitative, and two used both quantitative and qualitative approaches; 26 studies used cross-sectional data while five used longitudinal data. Although we did not focus specifically on intervention studies, we identified four in our review. Eight studies used probability samples and 23 used nonprobability samples.

Overall, it was difficult to summarize the literature on rural caregiving for two reasons. First, there was not a significant body of original research available. Second, numerous aspects have been examined under the broad topic of rural caregiving. For example, research on rural caregiving has examined residential differences in use of adult day care and in-home respite (Montoro-Rodriguez et al., 2003), rural/urban differences in the caregiving network that may affect stress and burden (Dwyer & Miller, 1990a, b), and medication use of rural caregivers compared with noncaregivers (Mort et al., 1996). Despite the diversity of the research objectives, we offer some discussion about what we know to date.

The majority of the studies included in our review examined health-related caregiver outcomes. Among the rural/urban studies, the most common outcomes

Table 7.1 Rural caregiving and related research literature

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Rural/urban comparative studies					
Bedard et al. (2004)	QN/CS: Assess health impact on caregivers providing care to cognitively impaired adults in rural and urban settings.	Rural = Community of <15,000 Urban = Community of ~125,000	None provided	NP: 20 rural and 17 urban caregivers of persons with various forms of dementia (n = 37)	Rural care recipients had higher frequencies of behavior problems. Rural caregivers had access to fewer formal supports but did not report greater burden, poorer health status, or fewer healthy behaviors than urban caregivers. For rural caregivers, higher reports of burden were associated with fewer healthy behaviors.
Coward et al. (1990)	QN/CS: Assess whether helping networks (no assistance, informal only, informal and formal, and formal only) of impaired older adults vary by residence and severity of impairment.	Urban = Standard Metropolitan Statistical Area – (1) central and (2) non-central cities Rural = Non-Standard Metropolitan Statistical Area	None provided	P: 1984 Supplement on aging to the national interview survey (n = 16,148)	Among impaired older adults, helping network configuration did not differ by residence. The severely impaired older non-metropolitan sample was more likely to continue to rely on informal helpers than those from the other locales.

(continued)

Table 7.1 (continued)

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Dwyer & Miller (1990a)	QN/CS: Investigate by residence differences in impact of caregiving network characteristics on primary caregiver stress and burden. Assess whether stress and burden are explained by similar variables.	Rural = Open country/non-farm or farm setting of $<2,500$ Small city = City/town/village of $\geq 2,500$ but $<50,000$ Urban = City of 50,000–250,000, suburb of large city, or large city with $>250,000$	Primary caregiver = Individual who reported the greatest number of hours per day spent providing care	P: Care receivers 65 years or older from the 1982 long-term care survey matched with their primary caregivers from the national survey of informal caregivers (n = 1,388)	The relationship between caregiving networks and caregiver stress and burden were not homogeneous across residence. In the rural sample, age of caregiver increased stress but not burden. In the small city sample, the relationship between caregiver and care receiver and their impairment in activities of daily living were both associated only with burden.
Dwyer & Miller (1990b)	QN/CS: Examine residential differences in characteristics of caregiving networks that may impact primary caregiver stress and burden.	Rural = Open country/non-farm or farm setting of $<2,500$ Small city = City/town/village with $\geq 2,500$ but $<50,000$ Urban = City of 50,000–250,000, suburb of large city, or large city of $>250,000$	Primary caregiver = Individual who reported the greatest number of hours per day spent providing care	P: Care receivers 65 years or older from the 1982 long-term care survey matched with their primary caregivers from the national survey of informal caregivers (n = 1,388)	There were residential differences in characteristics of the caregiving network but minimal variation in caregiver stress and burden. Rural care recipients had fewer paid helpers, least number of paid helpers assisting with at least one activity of daily living, and received help with the fewest number of instrumental activities of daily living. Rural caregivers had the highest mean stress levels but the lowest average burden levels.

Kosloski et al. (2002)	QN/CS: Understand role of culture in use of respite services. Culture defined as ethnicity, relationship between care recipient and provider, and rural/urban location.	None provided	None provided	P: Caregivers of Alzheimer's patients participating in Alzheimer's disease demonstration grants to states (n = 315)	Urban and rural respondents were more similar than different regarding their attitudes and beliefs surrounding caregiving. Urban respondents compared to rural regarding family relationships reported higher obligation to care, higher respect for elders and regarding perceptions of formal service delivery, reported more communication difficulties, and more red tape. Urban and rural respondents did not differ on affection for elder, family values, guilt at respite use, government assistance, satisfaction with help, spirituality, support from congregation, and for formal service delivery expectations, access, friendliness, and shared values.
McCabe et al. (1995)	QN/CS: Examine the relationship between demographic and personal characteristics of rural and urban Alzheimer's disease caregivers and use of available services.	Rural = Areas with <2,500 Urban = Areas with ≥2,500 Metropolitan = Cities with ≥15,000	None provided	P: Nebraska residents who received an Alzheimer's newsletter (n = 212)	Urban areas had more services available. Rural caregivers used available services proportionately more than urban caregivers.

(continued)

Table 7.1 (continued)

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Meyers & Gray (2001)	QN/CS: Investigate the relationship between primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden.	None provided	None provided	NP: Primary caregivers of patients enrolled in hospice for more than 2 weeks in Washington and Idaho (n = 44)	Caregivers who lived in more densely populated areas were more likely to experience poorer quality of life, and greater burden. There was no association between residence and satisfaction with hospice care.
Montoro-Rodriguez et al. (2003)	QN/CS: Evaluate practice-oriented and behavioral models of service use in their ability to explain adult day care and in-home respite service use among caregivers of Alzheimer's patients.	Rural = <50,000 Urban = ≥50,000	None provided	NP: Primary caregivers receiving respite services who could be contacted and were willing to participate (n = 1,311)	Residence was not associated with likelihood of using adult day care, but rural caregivers were less likely to use in-home respite services. Residence was not associated with service use for African Americans, Whites, or Hispanics. Urban residence was negatively associated with in-home respite use for Hispanics and positively associated for Whites.
Smith & Bell (2005)	QN/L/I: Examine 6 month outcomes of an intervention consisting of education, training, and service access among rural and urban dementia caregivers.	Rural = <2,500 Small cities or towns = <50,000 Urban = 50,000–100,000	None provided	NP: 54 rural and 42 urban caregivers for persons with dementia recruited through local Alzheimer's Association offices (n = 96)	Rural and urban caregivers did not differ on depressive symptoms at baseline but rural caregivers symptoms significantly improved 6 months later. Rural caregivers were less likely to use support groups (17% vs. 47%) at baseline but no difference at 6 months.

Tornatore & Grant (2004)	QN/CS: Investigate family caregiver satisfaction after nursing home placement of relative with dementia.	None provided	None provided	P: Family caregivers in Minnesota (n = 285)	Family caregivers in rural areas were more satisfied than their urban counterparts.
Wood & Parham (1990)	QN/CS: Identify differences in coping with caregiver strain of ethnic or cultural origin among Whites and African Americans from rural and urban locales.	Rural = All open country, unincorporated areas, and incorporated areas with a total of ≤25,000 except those areas adjacent to an urbanized area (≥50,000) with 10,000	None provided	NP: Women who were primary caregivers of relatives with Alzheimer's disease (n = 85)	Rural African Americans sought information less frequently compared to the other groups. Rural Whites prayed less as a coping strategy than rural African Americans or urban Whites. Urban caregivers tended to think of themselves as being in a comparatively better situation than did rural caregivers. Urban caregivers reported more instrumental support from Alzheimer's family group members and reported more psychosocial support from family and friends.
Rural only studies					
Browder (2002)	QL/CS: Identify how women deliberating decisions and implementing decisions describe their views about caregiving.	None provided	None provided	NP: Informal female caregivers (n = 18)	Women implementing decisions experienced caregiving in a more positive light and reported less stress than women deliberating decisions who expressed feeling vulnerable, self-doubt, and stressed.

(continued)

Table 7.1 (continued)

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Butler et al. (2005)	QN/CS: Identify levels and predictors of depression and burden among rural caregivers.	None provided	None provided	NP: Rural family caregivers (n = 62)	Caregiver burden and depression were highly correlated. Caregiver burden and depression were not related to demographics but related to other study measures including isolation, knowledge of caregiver tasks, caregiver task difficulty, and family support.
Clancy Dollinger et al. (2006)	QN/L/I: Present one case example.	None provided	Caregivers = Self-identified individuals who were caring for an older adult family member or friend age 50 years or older	NP: Case example (n = 1)	Case example outcome scores on health-related quality of life, social functioning, psychiatric symptoms, and perceived stress after completion of the 8-week intervention indicated some improvement and the improvements remained stable 6 months later.
Connell et al. (1996)	QL/CS: Identify myths and misconceptions about dementia, barriers to effective service delivery, and community strengths.	None provided	None provided	NP: Service providers and family caregivers (n = 138)	Several barriers to effective service delivery were identified, including lack of coordination of health and social services agencies, prohibitive cost of services, lack of available services and appropriate referrals, restrictive reimbursement policies, and understaffing and high demand for existing services.

Cuellar (2002)	QN/CS: Compare self-efficacy among African American and White female caregivers of post-stroke, bedbound older adults in rural Mississippi.	None provided	None provided	NP: 36 African American and 36 White caregivers of bed bound older adults (n = 74)	African American caregivers reported lower self-efficacy, stress, depression, and higher life satisfaction than White caregivers.
Dellasega & Zerbe (2002)	QN/L/I: Identify indirect benefits to rural family caregivers of older individuals recently discharged from hospitals randomly assigned to supportive advanced practice nurse or control intervention.	None provided	Caregivers = Self-identified individuals who provided assistance with two or more activities of daily living and/or instrumental activities of daily living for frail individuals age 65 years or older	NP: Caregivers of frail rural older adults discharged from an urban hospital to home in rural areas (n = 32)	The intervention group had higher self-rated emotional health scores, fewer emotional symptoms, fewer depressive symptoms, and lower stress scores than the control group.
Eaves (2006)	QL/CS: Examine rural African American family caregiving for older stroke survivors recently discharged from rehabilitation centers.	Rural counties ranging from 17,265 to 38,892	None provided	NP: 8 families participated which included 8 stroke survivors, 8 primary caregivers, and 18 secondary caregivers	Families coped with transitions using a four-stage basic social process of striking a balance: (1) deciding to care, (2) dividing care, (3) protective care, and (4) coming to terms.
Johnson (1998)	QL/CS: Investigate positive and negative experiences of caregiving.	None provided	None provided	NP: Caregivers of stroke survivors who have been in the caregiving role for at least 6 months (n = 24)	Five themes characterizing the caregiving experience emerged: sense of loyalty, acceptance, sense of feeling good, satisfaction associated with helping others, and burden associated with lifestyle change.

(continued)

Table 7.1 (continued)

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Kaye et al. (2003)	QN & QL/L/I: Investigate impact of physician screening and intervention on negative caregiver health outcomes.	None provided	None provided	NP: Recruitment was done by physicians who identified caregivers who reported feelings of stress and burden, Of those identified and willing to participate, they were then contacted by a caregiver specialist for assistance (n=52)	After the intervention, caregivers reported increased assistance with task frequency and difficulty for the care recipient, increased caregiver knowledge, and decreased levels of depression.
Kivett et al. (2000)	QN/L: Identify demographic characteristics of very-old rural adults, their physical, psychological and social status, changes as they aged and their needs and sources of social support.	None provided	None provided	P: Adults 85 years and older (n=49)	African Americans were more physically and economically disadvantaged than Whites. Physical dependence was most notable in household maintenance and financial management. Participants depended more heavily on informal than formal supports.

Kosberg et al. (2007)	QN/CS: Learn whether or not there are differences in the caregiving experiences between a sample of African American and White caregivers.	Residents of rural counties in Alabama as defined by the U.S. Census Bureau	Primary family caregivers = self-described as such and provided at least 10 h a week of in-person assistance to meet the physical and/or emotional care needs of the care recipient	P: 67 African American and 74 White family caregivers	Caregivers were high on religious activities and almost all used religion as a coping strategy. Compared to African American caregivers, White caregivers were more likely to engage in private religious activities, use more medications, engage in acceptance and humor, perceive care recipients to be more depressed, have higher scores for burden and less likely to engage in organized religious activities and care for other family members in addition to parents.
Ladner & Cuellar (2002)	QN/CS: Determine if informal hospice family caregivers were depressed and if they were being treated with conventional or non-conventional interventions.	Rural = All territory, populations, and housing units located outside of urban areas or clusters as defined by the U.S. Census Bureau	Informal caregiver = Adults 18 years or older who provides unpaid care for a hospice patient at least 8 hours a day in their home	NP: Rural hospice caregivers recruited from hospice home health agencies (n = 30)	Forty percent of hospice caregivers were depressed with 17% on medication for depression. Few caregivers were using non-conventional therapies for depression. White caregivers were more depressed than African American caregivers.
Morgan et al. (2002)	QN & QL/CS: Identify challenges in caring for persons with dementia, estimate the number of older persons with dementia, and describe environments of pro-	Rural = <10,000	None provided	NP: Family caregivers (n = 9) P: Formal caregivers (n = 13)	Participants identified barriers to the use of formal services: stigma of dementia, lack of privacy, beliefs and attitudes, lack of awareness, financial barriers, acceptability of services, and service delivery challenges.

(continued)

Table 7.1 (continued)

References	Study objective	Residence definition	Caregiver definition	Sample	Results
Mort et al. (1996)	QN/CS: Compare prescription and over-the-counter psychotropic medication and social drug use of older caregivers of patients with dementia and older noncaregivers.	None provided	Caregiver = People caring in their home for individuals diagnosed with dementia	NP: Older adult caregivers (n = 30) and noncaregivers (n = 30) in the midwest region of the U.S.	A higher proportion of caregivers compared to noncaregivers took psychotropic agents (43% vs. 3%).
Reed & Claunch (2002)	QL/CS: Examine spousal coping after farmer husbands suffered a permanently disabling injury.	Rural = Agricultural economic base, specifically farming operations	Caregiver = Wife of permanently disabled farmer	NP: Farm wives from Kentucky, Tennessee, and Iowa (n = 12)	Four themes in the coping process were identified: survival, sheltering, sacrifice, and stabilization.
Ross et al. (2003)	QL/CS: Identify successful coping strategies used by resilient informal and formal caregivers.	None provided	None provided	NP: MSW students and personal acquaintances of the students who were caregivers (n = 23)	Coping strategies included: (1) distancing themselves physically and emotionally, (2) exercise, (3) hobbies, (4) emotional support, (5) religious faith, (6) use of humor.
Sanford et al. (2005)	QN/CS: Examine relationships among stress, caregiver burden, and health status of rural caregivers.	Rural = Places with <2,500 and open territory as defined by the US Department of Agriculture Economic Research Service	None provided	NP: Informal caregivers in rural Alabama and Mississippi (n = 63)	Stress, burden, and health status among rural caregivers were related. Variance in health status was accounted for by stress and caregiver burden.

Sanford & Townsend-Rocchiccioli (2004)	QN/CS: Compare self-reported health of rural caregivers and the general population.	Rural = Areas of open country that are sparsely populated and remote from large, metropolitan cities	Caregiver = Person who assists with activities of daily living and/or with 2 instrumental activities of daily living without payment	NP: Caregivers from rural southwest Alabama and southeast Mississippi (n = 63)	More caregivers considered themselves in poor/fair health and fewer reported very good/excellent compared with people in the general population.
Shenk (1991)	QL/CS: Examine rural elder females' role as active manipulators of social support systems through which they meet their perceived needs and needs of others in their network.	Self-defined by study participant	None provided	NP: Older women in central Minnesota (n = 30)	Women were entrenched in their social support systems and both gave and received care. Their support systems reflected a lifelong pattern of exchanging emotional and instrumental support with family, friends, and neighbors. They used services to fill gaps in informal support without getting involved in formal support network.
Silveira & Winstead-Fry (1997)	QN/CS: Examine physical and psychological needs and identify unmet needs of patients with cancer and their caregivers.	None provided	Caregivers = Family members or friends who brought patient to the health care facility	NP: Patients with cancer (n = 30) and their caregivers (n = 30) in Vermont	Using the Patient Needs Scale, care recipients identified 49% and caregivers identified 41% of the needs. Over 50% of both groups identified very important needs in personal care, involvement with health care, and interpersonal interaction. Care recipients and caregivers reported 5% and 14% of needs were unmet, respectively.

QN, quantitative research; *QL*, qualitative research; *CS*, cross sectional; *L*, longitudinal; *I*, intervention; *P*, probability sample; *NP*, nonprobability sample included caregiver mental and physical health and use of formal and informal services. With respect to residential differences in mental and physical caregiver health outcomes, the studies that we reviewed do not suggest the presence of a clear and consistent rural/urban difference. For example, rural caregivers reported higher mean stress levels but lower mean burden levels than urban caregivers (Dwyer & Miller, 1990b). Other research suggested that caregivers in more densely populated areas were more likely to have comparatively greater burden and poorer quality of life (Meyers & Gray, 2001), while a third study found no residential differences in caregiver depressive symptoms (Smith & Bell, 2005).

Research on residential differences in service use generally indicated that rural caregivers and care recipients were more likely to use informal supports than those in more urban areas (Bedard et al., 2004; Coward et al., 1990) and, with the exception of one study (McCabe et al., 1995), were less likely to use formal services (Bedard et al., 2004; Dwyer & Miller, 1990b; Montoro-Rodriguez et al., 2003). Bedard et al. (2004) found that rural caregivers were more likely to use informal help compared to urban caregivers and reported less available formal support, with no residential differences in formal service use. Another study reported no clear evidence of rural/urban differences in the availability of informal support, but urban care recipients received more paid assistance than rural care recipients (Dwyer & Miller, 1990b). Although this suggested similar availability of informal support across residence, another study determined that nonmetropolitan older adults were more likely than metropolitan older adults to use informal support (Coward et al., 1990). McCabe et al. (1995) reported a greater availability of services in urban areas, although rural caregivers used services proportionately more. Other research concluded that residence was not associated with adult day care use, but rural caregivers were less likely to use in-home respite services (Montoro-Rodriguez et al., 2003).

The predominant outcomes examined in the rural-only studies were the mental and/or physical health of the caregiver and caregiving coping strategies. Findings indicated that burden was positively associated with depression among rural caregivers (Butler et al., 2005). Among rural caregivers, African Americans had lower self-efficacy, stress, depression, and higher life satisfaction than Whites (Cuellar, 2002). A second study on racial differences in rural caregiving also reported that African-Americans were comparatively less depressed, but showed higher burden than White caregivers (Kosberg et al., 2007). Finally, rural caregivers were more likely than noncaregivers to report poor or fair self-rated health (Sanford & Townsend-Rocchiccioli, 2004). We are unable to conclude from the rural-only studies how the rural environment directly influenced the caregiving experience, since this was not an explicit objective in the studies that we reviewed.

Although most of the studies included in our review did not use an identifiable theoretical or conceptual approach, there were eight different theories or conceptual models used in the literature. Kosloski et al. (2002) developed their own conceptual model regarding culture and respite use. Meyers & Gray (2001) and Tornatore and Grant (2004) both framed their research with the stress process model (Pearlin et al., 1990). Montoro-Rodriguez et al. (2003) used the Andersen behavioral model (Andersen, 1968). Browder (2002) used the individual mindset model (Taylor & Gollwitzer, 1995). Clancy Dollinger et al. (2006) used the perceived stress model of caregiver burden (Chwalisz, 1996). Cuellar (2002) integrated a self-efficacy theory (Bandura, 1977) and a stress and coping theory (Lazarus, 1966; Lazarus & Folkman 1984). Johnson (1998) used both a stress and coping theory (Lazarus, 1966) and Weiner's attribution theory (Weiner, 1980). Overall, the literature on rural caregiving did not have a predominant theory to help guide the research and delineate the caregiving experience.

In addition, from our review of the original research as well as the broader rural caregiving literature, we determined that much of the literature on rural caregiving is based on certain beliefs that are not necessarily supported with empirical evidence. These five common beliefs are as follows:

1. Rural caregivers are at a disadvantage compared to their urban counterparts due to a lack of formal services that could assist them in the caregiving role.
2. Rural caregivers are at a disadvantage because, even if supportive formal services were available, they would not use them for two reasons. First, rural residents, on average, have lower educational levels than their urban counterparts, and persons of lower educational levels are less likely to avail themselves of formal community services. Second, formal services are not used because of the prevailing rural value of self-sufficiency.
3. Rural caregivers are at a disadvantage because older adults in rural areas, who are the potential care recipients, are in poorer physical health than their urban counterparts.
4. Rural caregivers are at an advantage because rural families have strong ties across multiple generations. Rural residents have a larger network of informal helpers, with adult children remaining nearby who are willing to care for aging parents.
5. Rural caregivers are at a disadvantage because younger generations, who are the potential caregivers, are leaving rural areas for education and employment, and/or adult children do not live nearby.

Three of the five beliefs suggest that rural caregivers are at a disadvantage compared with caregivers in more urban areas due to a lack of formal supportive services or because of the characteristics of the residents themselves. As outlined in the first belief, some of the studies in our review stated without empirical support that an overall lack of formal services in rural areas has resulted in negative health-related caregiver outcomes. Although health care and other supportive services are almost universally less available in rural areas (Schur & Franco, 1999), it is unclear whether this adversely affects rural caregivers. The second belief is based largely on the premise that persons of lower educational levels are less likely to avail themselves of formal community services (Kemper, 1989; Miller & Mukherjee, 1999). Although it is true that rural residents, on average, have lower levels of education than their urban counterparts, there is no empirical evidence to suggest that rural caregivers would choose not to use formal services if these services were available. The third belief states that typical rural care recipients, frail older adults, are in worse health compared to their urban peers. However, results from research that has examined health differentials between rural and urban older adults presents a mixed picture where it is difficult to definitively say rural older adults consistently have poorer health.

Thus, there is no reason to conclude that rural caregivers experience greater stress and/or burden than their urban counterparts due to worse health of the care recipients.

The final two beliefs are based on preconceived ideas about how the changing rural family and demographic structure are impacting provision of care in rural areas. One states that rural caregivers are at an advantage due to strong family ties across multiple generations residing nearby. Yet, the evidence is mixed regarding whether rural or urban elders have stronger networks and greater access to informal caregivers (Glasgow, 2000). In fact, some researchers have argued that small rural population size negatively impacts the development of social relationships. Rural dispersion and distance limit the opportunities for social interaction and as a consequence, rural residents have weaker social ties (Hofferth & Iceland, 1998; Wilkinson, 1991). Moreover, families in rural America are moving away from the ideal of an intact family embedded in supportive kin and community networks. With each passing decade, rural household size has been decreasing at a more rapid rate than urban households (MacTavish & Salamon, 2003). Families have also developed greater resemblance to the demographic profile and structure of the average American family (Teachman et al., 2000). The final belief posits that rural caregivers are at a disadvantage due to the out-migration of younger generations. Over the past decade, there has been a decline in moving rates of rural and urban persons of all ages (Schachter, 2004) and, when migration does occur, it tends to be toward certain types of areas. Working-age people do tend to migrate for employment from rural to urban areas (Johnson, 2003). However, the impact of this out-migration on caregiving, if any, has not been clearly established.

Although we identified these general beliefs in the rural caregiving literature, it is unknown to what extent these beliefs have influenced researchers, policy makers, and the general public. Some of these beliefs are reminiscent of the 1993 Vital and Health Statistics Report entitled, "*Common Beliefs About the Rural Elderly: What Do National Data Tell Us?"* The report begins with ten common beliefs about the rural elderly, which suggest the existence of many misconceptions about rural populations overall (Van Nostrand, 1993). It is critical, particularly at the early stages of this area of research, that we do not perpetuate these assumptions without empirical support.

Methodological Issues in Rural Caregiving Research

Population aging and shifts in migratory patterns underscore the importance of developing a literature on rural caregiving, but the research we reviewed was characterized by a number of methodological limitations. These issues also contributed to our inability to definitively explain the role of the rural environment on caregiving. While these problems are not unique to this research topic, we hope that outlining them here will aid future research in answering what is *rural* about rural caregiving. As presented in Table 7.2, we have identified the methodological issues common to

Table 7.2 Methodological issues

References	Theory or conceptual model	Definitions		Probability sample	Longitudinal data	Objective or clinical measure(s)	Presented racial/ethnic results
		Rural	Caregiver				
Rural/urban comparative studies							
Bedard et al. (2004)		✓					
Coward et al. (1990)		✓		✓			
Dwyer & Miller (1990a)		✓	✓	✓			✓
Dwyer & Miller (1990b)		✓	✓	✓			
Kosloski et al. (2002)	✓			✓			✓
McCabe et al. (1995)		✓		✓			
Meyers & Gray (2001)	✓						
Montoro-Rodriguez et al. (2003)	✓	✓					✓
Smith & Bell (2005)		✓			✓		
Tornatore & Grant (2004)	✓			✓			
Wood & Parham (1990)		✓					✓
Rural only studies							
Browder (2002)	✓						
Butler et al. (2005)							
Clancy Dollinger et al. (2006)	✓		✓		✓		
Connell et al. (1996)							
Cuellar (2002)	✓						✓
Dellasega & Zerbe (2002)			✓		✓		
Eaves (2006)		✓					✓
Johnson (1998)	✓						
Kaye et al. (2003)					✓		
Kivett et al. (2000)				✓	✓		✓

(continued)

Table 7.2 (continued)

References	Theory or conceptual model	Definitions		Probability sample	Longitudinal data	Objective or clinical measure(s)	Presented racial/ ethnic results
		Rural	Caregiver				
Kosberg et al. (2007)		✓	✓	✓			✓
Ladner & Cueller (2002)		✓	✓				✓
Morgan et al. (2002)		✓					
Mort et al. (1996)			✓				
Reed & Claunch (2002)		✓	✓				
Ross et al. (2003)							
Sanford et al. (2005)		✓					
Sanford & Townsend-Rocchiccioli (2004)		✓	✓				
Shenk (1991)		✓					
Silveira & Winstead-Fry (1997)	✓		✓				

the research on rural caregiving, with some clearly being more problematic than others.

These issues include:

1. Lack of an underlying theory in research design
2. Failing to provide operational definitions of key variables
3. Non-probability sampling in quantitative studies, which limits generalizability of results
4. Cross-sectional data analysis, rather than using longitudinal designs
5. Overreliance on self-report data and underuse of objective measures
6. Insufficient samples of minority racial/ethnic groups

Need for Theory

Nine of the 31 studies reviewed included an explicit description of a theoretical model or conceptual framework. Although there are no theories specific to rural caregiving, existing theories drawn from the broader caregiving literature could easily be applied to rural settings. A well-known theory of caregiving that was used in two of the reviewed studies was the stress and coping theory (Folkman et al., 1987; Lazarus, 1966; Lazarus & Folkman, 1984). Another theory that could be used for rural populations is the sociocultural stress and coping model (Knight et al., 2000). We believe that these models are particularly relevant to rural caregivers because they emphasize the role of the environment and culture, respectively, on the stress and coping process. The stress and coping theory posits that the person and the environment are in a dynamic and reciprocal relationship. Stress is a person–environment relationship that is appraised by the individual as burdening his or her resources and endangering well-being. Coping is conceptualized as the person's efforts to manage internal and external demands that are appraised as taxing or exceeding one's resources (Folkman et al., 1986). If this theory were to be applied to rural research, for example, the rural environment could be examined as both a stressor and a source of coping. The sociocultural stress and coping model argues that between ethnic groups specific cultural differences will directly affect both stress appraisal and coping with the caregiving situation (Knight et al., 2000). This model could be modified for research on rural caregiving by using residence in the model instead of, or in addition to, ethnicity as a source of individual variability. As more research becomes available, these and other theories could be tested to change current preconceptions, beliefs, and speculation about rural caregiving.

Definitions

Terms such as "rural," "rural culture," and "caregiver" are often used in the literature and are essential to the development of research and practice in this area. Inconsistency in the operational definitions of these terms has important implications for research.

Problems related to the different definitions of “rural” have been well-documented, and research on “rural” produces different results depending on which definition is used. According to the Rural Policy and Research Institute (n.d.), there is no standard definition of “rural” used in research and policy making. This can be problematic because the residential areas classified as rural and nonmetropolitan do not perfectly overlap. Some caregiving studies described their sample as rural but failed to explain the criteria used for designating a community or population as rural. In our sample of the literature, 16 of 31 studies provided an operational definition of rural. We also found that definitions were more common among the rural/urban comparative studies than the rural-only studies.

Our recommendation is to clearly define residence as a unit of analysis. For the purposes of some research, the standard rural/urban or non/metropolitan distinction may be sufficient. However, to truly discover how the rural environment may influence the caregiving experience, better macro-level measures of where one resides need to be developed. The area associated with a particular place may be very different from what is defined by the geographical boundaries of town or county. Residential communities may have political or social boundaries, yet much of the existing data on rural caregiving are disconnected from the concept of residence. In addition, abstract concepts such as rural culture need to be more clearly defined and quantified through the development of valid measures.

The range of definitions for “caregiver” is also wide. Caregivers can be defined according to the tasks they perform for the care recipient (e.g., Sanford and Townsend-Rocchiccioli, 2004; Silveira & Winstead-Fry, 1997) or the amount of time they provide care within a given time frame (e.g., Ladner & Cuellar, 2002). More commonly, however, the authors of the studies reviewed did not explicitly state what criteria were used to define “caregiver.” Only 10 of the 31 studies reviewed provided a definition of what constituted a caregiver. Another problem related to defining “caregiver” is the use of alternate terminology such as helping network, primary helper, or informal support systems. When these key constructs are not defined, or when definitions vary across studies, it becomes difficult to develop a complete understanding of the rural caregiving experience. The field is transitioning into one wherein operational definitions of key variables are crucial for comparison across studies. Our recommendation is to include language in journal editorial requirements that remind authors to provide definitions of key variables. This will be particularly important as meta-analyses become more popular in peer-reviewed publications.

Sampling

Eight studies that we reviewed used probability samples and 23 studies were based on nonprobability samples. Probability sampling techniques, which specify the likelihood that any member of a population will be selected for the sample (Agresti & Finlay, 1986), make it possible to make generalizable statistical inferences to the entire research population. Nonprobability sampling in quantitative research does not allow for this inference. Research on rural caregiving has often used small samples, which are restricted to a particular geographic region, thus limiting the generalizability of the results (Dwyer & Miller, 1990a). Purposive sampling supports transferability by providing enough information for other observers to judge how the results might apply to other contexts (Erlandson et al., 1993). We recognize that the samples used in qualitative research are not intended to represent larger populations, but are used because they can provide in-depth information and help generate hypotheses. Thus, we recommend that future recruitment efforts for quantitative studies use probability sampling as a means for improving the generalizability of results, and that qualitative studies expand the range of rural populations included in these studies.

Cross-Sectional Data

Only five of the articles we reviewed employed a longitudinal study design, and four of these were intervention studies. Longitudinal studies would add to the research on rural caregiving by providing data on change in caregiving over time, including changes experienced both by the care recipient and provider. Information on change over time might include the health of the care recipient, formal service use, the amount of support provided to the caregiver, or the health of the care provider. We submit that longitudinal studies are needed to better understand the dynamic experience of caregiving.

Self-Reported Data

In addition to definitional and design issues, the entire sample of research on rural caregiving that we reviewed used self-report data. Although this is a convenient and meaningful mode of data collection, these data are sensitive to variations in assessment and subject to participant bias. Caregivers may underreport problems due to denial or a lack of awareness of the effects of caregiving on mental and physical health (Robinson & Austin, 1998). The use of objective measures of the caregiving experience should be explored. Physiological markers of stress, for instance, are becoming more common in caregiver studies (e.g., Bauer et al., 2000; Davis et al., 2004). None of the research reviewed for this article collected physiological markers of stress. Self-report measures used in conjunction with physiological markers may give a more comprehensive and reflective picture of health. Using both forms of measurement can also help clarify whether response bias is more prevalent in certain residential areas.

Racial/Ethnic Diversity

Few studies that we reviewed examined racial/ethnic variability in the caregiving experience across types of residence. Although 16 studies had non-White participants, only nine articles examined results by race/ethnicity beyond a simple description of the sample characteristics. Discussions of racial/ethnic diversity typically focus on metropolitan areas. Although rural areas have comparatively less racial/ethnic diversity than urban areas, rural America has become more diverse over the past decade (Johnson, 2003). We feel that the lack of attention to the increasing heterogeneity of rural areas is a notable limitation in the body of research on rural caregiving.

Barriers to Conducting Research in Rural Communities

Researchers face many obstacles to conducting caregiving research and/or implementing programs in rural communities. These barriers are particularly salient within the context of the rural environment and include elements of predominant rural norms and values. Distrust of outsiders and valuing privacy, independence, and self-reliance (Wilkinson, 1991) *may* influence research on rural caregiving. Potential research participants may mistrust a team of researchers who are not from their community (Smith et al., 2002). In addition, a research project may be perceived as an invasion of privacy or as interference with local issues (DiBartolo & McCrone, 2003). Motivating caregivers to participate in research can create another barrier because caregivers are likely to have increased feelings of stress and excessive time demands (Dura & Kiecolt-Glaser, 1990). Further, recruiting participation in longitudinal and/or qualitative studies may be more challenging because they can involve a time-consuming long-term relationship (Preloran et al., 2001). In rural communities specifically, family members and service providers may feel protective of potential study participants (Quandt et al., 1999).

Whether the project succeeds in recruiting research participants and gaining community cooperation depends largely on the team's initial approach. To prevent negative perceptions of research and maximize participation, it is critical that researchers learn as much as possible about a rural community prior to the study and share common goals for conducting the project. For instance, the researcher may not have a good understanding of the community's history, values, and the significance of local institutions and organizations. In addition, an inherent tension exists between researchers and the community that arises out of misunderstandings of a project's goals and potential outcomes. Rural community residents may feel the answers to their issues are obvious and expect the research to lead to quick action (Quandt et al., 1999). In rural areas with high poverty rates and other social problems, residents may feel over-studied and wonder why researchers come and go without producing any tangible change in the community residents' quality of life. To avoid this problem in research on rural caregiving, a researcher must take the time to identify local individuals and organizations to help legitimize a project. One successful strategy for researchers is to identify a community gatekeeper who can serve as an ambassador to the community for the project (St. Lawrence & Ndiaye, 1997).

Many of the barriers to conducting caregiving research in rural communities are inherent in the infrastructure of the rural environment. Resources necessary for conducting research and/or implementing wellness programs are not as plentiful in rural areas as they are in urban areas. Based on previous research efforts with rural populations, the following structural barriers can make conducting a large study in a rural area difficult:

- Limited public transportation
- Traveling long distances
- Limited hotel/motel accommodations
- Few local persons with needed skills to hire
- Limited access to facsimile machines, photocopy services, high-speed Internet
- Limited cellular telephone reception
- Limited access to an overnight courier

In a rural community, an effective way to conduct research in general, and caregiving research specifically, is to engage in community-based participatory research (CBPR). CBPR is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the goal of combining knowledge with action and achieving social change to improve health outcomes. There are eight principles of CBPR (Israel et al., 1998, pp. 178–180):

1. Recognize the community as a unit of identity. A community can be defined as a neighborhood, ethnic group, or small town.
2. Build on the strengths and resources of the community. The strengths and resources can include certain skills of a community leader, churches, and other community-based organizations.
3. Facilitate cooperative and collaborative relationships at all phases of the project. Allow parties to contribute to the project as equal members, including identification of the problem, data collection, interpretation of results, and translating the research into practice.
4. Integrate knowledge and action to provide benefits to all partners.
5. Promote empowerment with respect to social inequalities. CBPR involves reciprocity between the researchers and the community members with respect to knowledge, skills, capacity, and power.
6. The CBPR is a cyclical and iterative process that involves all steps of the research process including, at times, identification of the problem.
7. Address health from a positive and ecological perspective. The ecological model takes into account biomedical, social, economic, cultural, historical, and political determinants of health.
8. Disseminate research findings to all partners. Allow community members to review press releases, presentations, and publications in advance and coauthor reports and publications that reach and are useful to the community.

CBPR involves a long-term commitment; it is critical for researchers to continue to work with the community even when they are no longer funded to do so. CBPR has emerged, in part, to replace conventional research practices in communities. In many ways, conventional research has a contentious history and offers limited opportunities to improve the health and well-being of the people in these communities

(Israel et al., 1998; Manson et al., 2004). Research that focuses on a distinct characteristic, such as rurality, must take a different approach to conducting a meaningful research project. With rural caregiving, a successful project must employ culturally sensitive research methods similar to those described in the CBPR approach. Culturally sensitive methods are defined as methods that are responsive to and congruent with the values, beliefs, customs, and nuances of the specific culture of the research participants. Adapting conventional research approaches to take into consideration the rural community's norms and values can increase response rates and enhance validity of results, as well as demonstrate sensitivity and respect for the culture of the intended study participants (Shreffler, 1999).

What Is Needed: Future Directions

Our review of the past 18 years of rural caregiving literature demonstrates how difficult it is to conclusively say how and to what extent the rural environment might influence caregiving. Based on the literature reviewed, it is difficult to summarize the findings given the limited amount of published research, the diversity of topics examined, and the methodological issues that we described. Common outcomes examined in the literature included the health of the caregiver and formal and informal supportive service use. The research to date does not indicate that living in a more rural area consistently results in poor health outcomes for caregivers. Rural caregivers and/or care recipients appear to be more likely to use informal supports compared to their urban counterparts while those residing in more urban areas tended to have available and/or use formal services more. Clearly, more research is needed to better understand if and how the caregiving experience differs by residence.

We also outlined a number of methodological issues in the literature that must be addressed in order for research on rural caregiving to evolve. These issues included a lack of theoretical models or frameworks; absence of clearly defined variables; limited generalizability (in the case of quantitative research); lack of longitudinal designs; underuse of objective measures; and limited representation of racially/ethnically diverse samples. Similar issues (i.e., need for theory, attention to sampling, etc.) were identified in a review of the caregiving research with respect to race, ethnicity, and culture (Dilworth-Anderson et al., 2002). Of these issues, the ones that we found most prevalent included the absence of objective measures, limited use of longitudinal designs, insufficient samples of minority racial/ethnic groups, and lack of underlying theory in research design. While some of these issues are fundamentally more problematic than others, we felt that delineating them here is an important step toward addressing them.

In an effort to improve our understanding of the role of the rural environment in the caregiving experience, we have made the following recommendations for future research on rural caregiving: (1) use theory to inform study design, (2) define key variables, (3) use probability sampling techniques (in the case of quantitative research), (4) examine research questions longitudinally, (5) incorporate objective and/or biological measures, and (6) increase representation of non-White participants. Lastly, both qualitative and quantitative research have made different, complementary contributions to our knowledge of rural caregiving. An increasingly popular approach to research is using a mixed method design, which uses both qualitative and quantitative data collection and analysis. Mixed methods can be superior to single method designs and can answer questions that a single approach cannot (Teddlie & Tashakkori, 2003). Thus, our final and seventh recommendation is to employ a mixed method approach to answer research questions and capitalize on the strengths of both approaches, which will contribute to a higher-quality literature on caregiving in the rural context and a better understanding of the influence of the rural environment. With mixed methods, one method can provide greater depth, the other greater breadth, and together confirm or complement each other (Sale, et al. 2002).

A clear need exists to expand the types of populations studied in research on rural caregiving, as well as to improve the sophistication of measures and approaches used in data collection. If future research could address these issues, we believe that investigators would be better equipped to advance our understanding of how residence affects the caregiving experience. As the amount and quality of research in this area increases, it will be advantageous to systematically evaluate promising practices for caregiving interventions. Of the few intervention studies we reviewed, the methodological issues were similar to those identified in the other studies. As Morgan et al. (2002) have stated, “uniquely rural solutions” to issues of caregiving in rural areas must be found. The literature reviewed here represents a preliminary attempt to develop an understanding of rural caregiving. Although our review did not clarify how the rural environment affects the caregiving experience, it does provide a basis to further expand knowledge through additional research.

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Part III
Healthcare System Issues

Chapter 8
Workforce Issues in Rural Caregiving

Patricia A. Calico

> *There is hardly a more important responsibility than caring for others, whether that care is provided in a personal or professional context.*
>
> (Rosalynn Carter Institute for Caregiving, 2003, p. 4)

Workforce issues in rural caregiving are presented in a framework of practice, education and training, research, and policy development for the rural workforce. The current contexts as well as future needs are addressed. The practice section describes the health status of rural Americans and the current licensed and unlicensed workforce. Better access to education and training, diversity, and cultural competence are described in the education section. Rural workforce research and other research that impacts the workforce are addressed. Finally, policy related to rural health and the rural workforce is discussed.

Rural caregiving workforce issues are aligned with social, cultural, economic, and demographic changes in America. Rural lifestyles are historically associated with unique qualities and ideology involving family structure, values, self-reliance, and hardy social networks (Calico, 2002b; MacTavish & Salamon, 2003). Today, rural communities seek to maintain their uniqueness in the midst of change. As family farms disappear and natural resources are depleted, rural people may seek new areas of employment away from home, resulting in changes in the social structure and networks. So as workforce issues in rural caregiving are addressed, it is recognized that unique rural characteristics exist, that rural communities vary tremendously, and that these differences in the rural context across the nation influence caregiving at local levels.

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Practice

Providing quality health care in rural communities is inherently aligned with the quantity and quality of care providers and the systems of care in which they practice. It includes practice patterns, relationships among providers, and processes of care with patients, families, and communities. This section outlines the status quo for rural providers and concludes with an integrated vision for improving practice.

Current Status

Rural communities often have deficits in the supply of health-care providers including physicians, nurses, dentists, pharmacists, physical therapists, and others. Salaries, education, cultural opportunities, and professional isolation affect why professional health-care providers tend to practice in urban areas, where they are educated, rather than locating in rural areas. Recruiting and retaining professionals to deliver quality primary and specialty health care is a long-lasting challenge in rural communities (Committee on the Future of Rural Health Care [CFRHC], 2004; Hart et al., 2003; Rowley, 2004).

Yet, caregiver workforce issues are highly relevant to rural Americans because access to care is often limited and health needs are great. Rural residents have limited access to primary care, behavioral health care, and dental care. They are also less likely to have private health-care insurance than are urban citizens. Rural residents, particularly older adults, have more chronic health problems than residents in urban populations and they often need more services (Gamm et al., 2003a, b; Hart et al., 2003). Obesity is a growing problem and limited health literacy may prevent self-care behaviors (National Advisory Committee on Rural Health and Human Services [NACRHHS], 2005; Parker et al., 2003). Rural Americans, who work in farming, fishing, forestry, or mining, are at high risk for accidents and are particularly in need of quality emergency care systems (Bushy, 1991; Peek-Asa et al., 2004). Rural Americans who have traumatic accidental injuries experience disproportionately high mortality rates (Eberhardt et al., 2001; Peek-Asa et al., 2004). Those who survive injuries may experience a dearth of rehabilitation services, behavioral health services, or palliative care, and a delay in recovery. Suicide rates are also disproportionately higher in rural areas than in urban areas (Beresford et al., 2005; Eberhardt et al., 2001). Rural primary-care providers address the entire spectrum of patient needs and it fits that national and state rural health experts identify access to timely, effective primary care as a rural health priority (Gamm et al., 2003a, b).

Twenty five percent of Americans live in rural areas, yet, less than 11% of the nation's physicians (National Rural Health Association NRHA, 2006) and 20% of the nation's registered nurses (RNs) live and practice in rural communities. More data are available on the chronic shortage of rural physicians, yet the acute shortages among the nonphysician workforce are currently most critical (Hart et al., 2003). A national shortage of nurses is creating crisis conditions across the country and dentists are desperately needed in rural communities, as are technicians and other providers (Hart et al., 2003; Joint Commission on Accreditation of Healthcare Organizations JCAHO, 2002). The availability of rural providers affects access to care, quality of care, and the economy. For example, availability of diagnostic skills and capacity enables the delivery of services locally rather than requiring rural residents to drive to another town for services.

Nursing Personnel

Registered nurses and other nursing personnel constitute the largest number of health-care providers in rural areas (Hart et al., 2003). Basic entry-level registered nurses (associate, diploma, and baccalaureate graduates) provide essential health care, and in some rural communities are the only health-care providers (Bryant et al., 2003; Frontier Education Center FEC, 2004). Licensed practical (vocational) nurses also make particular contributions to long-term care services. Rural nurses often fill multiple roles that require them to have broad generalist preparation and to have good critical thinking skills (FEC, 2004). Bachelor of Science in Nursing (BSN) prepared nurses are highly valued for their critical thinking skills, leadership, and practice competence across settings (National Advisory Council and Nurse Education and Practice NACNEP, 2008); however, students are more likely to have to leave their communities to obtain their BSN degree and are less likely to return to practice in rural areas where financial incentives are lower (Pan & Straub, 1997). As a result, there are fewer BSN prepared nurses than associate degree graduates in rural areas (Skillman et al., 2006; Spratley et al., 2002).

Advanced practice registered nurses (APRNs) educated at the masters or doctoral levels assess, diagnosis, and prescribe in their practice as nurse midwives, nurse practitioners, nurse anesthetists, or clinical nurse specialists. While most APRNs practice collaboratively with physicians, some states permit APRNs to work autonomously (Hooker & Berlin, 2002). They are often the only providers of primary care, prenatal care, behavioral health care, and anesthesia services in communities and facilities with a critical shortage of health-care providers. Most APRNs are educated and employed as nurse practitioners (Spratley et al., 2002) and about 23% of nurse practitioners work in nonmetropolitan areas (Hooker and Berlin). They provide up to 10.3% of all outpatient primary care in some areas (Ricketts, 2005). Full-time base salaries for nurse practitioners, including all specialties and settings, average $84,250 (American Academy of Nurse Practitioners, 2008), but rural nurse practitioners earn lower average salaries than the national average (Tumolo & Rollett, 2005). Rural nurses may also have less opportunity for professional development and less flexible work hours than their urban colleagues (Bushy & Leipert, 2005).

Certified registered nurse anesthetists provide 70% of anesthesia care in rural hospitals and provide additional services, such as pain management, outside of the operating room (Garde, 2000; Seibert et al., 2004). Certified nurse-midwives also provide multiple services from prenatal care through labor and delivery, as well as health promotion. However, they face difficult challenges related to limited numbers of collaborating physicians, high malpractice rates, and decreasing reimbursements (NRHA, 2005b).

Nurses who practice in rural areas are likely to have a rural background, be educated in a rural environment, and want to make a difference in the community, especially in meeting the health-care needs of the underserved (Bushy & Leipert, 2005; CFRHC, 2004; Hart et al., 2002). Where RNs and APRNs are the sole skilled health-care provider, or one of two, the nursing shortage is acute as one nurse may be the defining factor in whether a rural or frontier area is underserved (FEC, 2004). Where there are no rural licensed nurses, care is likely to be provided by unlicensed personnel or family members and friends (FEC).

Physicians

Physician supply in rural America continues to be inadequate, with fewer than 11% of physicians in rural practice (Ricketts, 2000). Fewer primary-care physicians are choosing to practice in rural America and recruitment and retention of physicians continues to be a challenge (Brooks et al., 2003). There is an uneven distribution of physicians across the United States and losing or gaining just one rural primary-care physician has an enormous effect on access to care (Larson et al., 2003; Rabinowitz, 2004). Studies of rural physician practice patterns consistently support a positive association between rural practice and a rural upbringing (Bowman, 2005; Daniels et al., 2007; Looney et al., 1998; Rabinowitz et al., 1999). Pathman et al. (2004) also found higher retention rates when rural primary-care physicians owned their practices and when their call was two, or less than two, days per week. The proportion of female physicians is expected to approximate 40% of all physicians by 2010 (Darves, 2005), but fewer women practice in rural areas (19%) than urban areas (23%) (Doescher et al., 2000; Reschovsky & Staiti, 2005). Since call, referral networks, colleague support, and flexible schedules influence where women practice, there is concern of further decline in the number of rural primary-care providers (Bowman, 2005; Hart et al., 2003).

The current rural physician workforce is supplemented by international medical graduates (IMGs) who enter practice through the J-1 Visa Program. This program allows IMGs to pursue graduate medical education in the United States and then return to their home countries for at least 2 years before they can apply for a permanent visa in the United States. The 2-year home residency requirement can be waived to allow a physician to stay in the United States and practice in a Health Professions Shortage Area (HPSA) or a Medically Underserved Area (MUA), if the IMG is sponsored by a US or a state government agency (Rural Assistance Center, 2005). However, it is unclear whether current immigration policy makes unique contributions to reducing physician shortages (Lowell & Gerova, 2004). Data indicate that 2.1% of both US medical graduates (USMGs) and IMGs practice in rural underserved areas (RUAs), but US medical graduates are more likely to be family physicians and IMGs are more likely to be internists or pediatricians. The broad range of care provided by family physicians to children and adults, often including obstetrical care, is particularly valuable to rural communities (Fink et al., 2003).

Physician Assistants

Physician Assistants (PAs) practice in rural areas as mid-level providers of primary-care services. The PA role began in the 1960s as a way of increasing access to primary care, particularly for inner-city and rural underserved populations. Up to 23% of early graduates of PA programs were likely to practice in rural areas (Hooker & Berlin, 2002), but there are indications that rural PA practice is now beginning to decline (Larson et al., 2003). While PAs work in collaboration with physicians, they may be the only primary-care providers for several days during the week in some facilities where populations would otherwise not have local access to care (Hooker and Berlin).

Dentists and Dental Hygienists

Oral health care is severely compromised in rural communities. Rural residents are more likely than urban residents to have untreated dental cavities, to have lost all their teeth, or to have never seen a dentist. They often lack fluoridated water, a basic preventive measure against tooth decay (NRHA, 2005a; NACRHHS, 2004). Chronic oral disease is linked to systemic health problems such as cardiac disease and diabetes and potentially to low birth weight (U.S. Department of Health and Human Services HHS, 2000). Children experience more illness due to dental disease than to asthma and dental disease often results in absence from school and negative affects on their overall well-being (HHS, 2000; Mouradian et al., 2000). More states need to adopt policies for oral health care and treatment for children (Fisher-Owens et al., 2008).

The number of dentists in the United States has declined since the 1980s. The dentist-to-population ratio in rural America is 29 dentists for every 100,000 people compared to 43 dentists per 100,000 people in urban areas (Larson et al., 2003). Approximately, 35% of dentists are over age 55 and are likely to retire in the next 10 years (Henderson & Brand, 2003). The maldistribution of dentists limits access to care, especially for underserved populations who are characteristically low-income, racial or ethnic minorities, rural disabled, and at risk for poor health outcomes (HHS 2000; Mertz & O'Neil, 2002).

Dental hygienists provide oral health services and health promotion and prevention education. They work collaboratively with dentists as employees or contractors, and now in most states, hygienists may practice without the direct supervision of a dentist in some public health areas, such as long-term care, schools, and community-based clinics. In some states, they may provide basic restorative and treatment services (National Center for Health Workforces Analysis [NCHWA], 2004b). The number of dental hygienists is expected to grow significantly as preventive oral care gains importance and as dental hygienists develop an advanced practitioner role (Mertz & O'Neil, 2002). Minnesota is the first state to introduce Advanced Practice Dental Hygiene Practitioner legislation. A law was passed that created the role of Oral Health Practititioner (OHP) to work in collaboration with a licensed dentist. The OHP scope of practice will include "primary diagnostic, educational, palliative, therapeutic, restorative, simple extractions and prescriptive authority" roles (American Dental Hygienist Association [ADHA], 2008, paragraph 3). OHPs may only practice in underserved areas and may legally practice beginning in 2011.

Pharmacists

A national shortage of pharmacists is attributed to the expanded roles of pharmacists, the increased numbers and complexity of prescription drugs, and limited use of pharmacy assistants and technology (Health Resources and Services Administration [HRSA], 2000). More women are graduating from pharmacy school and their tendency to work fewer hours than men may also contribute toward the shortage (HRSA, 2000; Walton & Cooksey, 2001). It also takes more time to complete pharmacy education due to implementation of the entry-level pharmacy doctorate model and the acceptance of residency programs after graduation (Cooksey et al., 2002). Rural areas where many older adults reside are particularly vulnerable to pharmacist shortages as more prescription medications are prescribed and the Medicare drug benefit reforms take effect (Ricketts, 2005). Rural community pharmacists are likely to work independently with little opportunity for coverage that allows vacation or even sick leave. The economic viability of rural pharmacists is tenuous due to educational debts, lower reimbursements, and increasing liability costs, all of which affect profit margins (Jamison, 2006). Thus, several factors contribute to the shortage of pharmacists.

The challenge to reduce medication errors is particularly significant where rural pharmacists are often the missing team players in designing and implementing medication safety programs. Small rural hospitals are frequently staffed by part-time pharmacists who also staff nursing home pharmacies, and operate a retail practice. These pharmacists may not have adequate time and resources to improve medication safety practices and thereby enhance the quality of care for rural consumers (Casey et al., 2006).

Mental and Behavioral Health Professionals

Mental and behavioral health professional practitioners are also underrepresented in rural areas and primary-care providers address most mental health needs (Hartley et al., 2004; Ricketts, 2005). Primary-care providers and mental health professionals including psychiatrists, social workers, psychologists, counselors, and other therapists may not be educationally prepared to address rural needs (Hoge, 2004). Farmers and their families, in particular, are at risk for depression and other mental health and stress-related health problems given the changing economic and community environment (Fetsch et al., 2004; Simmons et al., 2008). The loss of tobacco as a cash crop, for example, created stress and challenges for many small farmers whose income was dependent on this crop. Rural residents need providers who understand unique rural cultural issues (Fetsch, et al., 2004). Family members also need education and training in how to support and cope with the mental health issues they face on a regular basis (Hoge, 2004).

Rural residents also lack mental health care because transportation is not available or they do not seek care due to an associated social stigma (Maiden, 2005; NACRHHS, 2004). In addition, mental health providers may not be available due to attrition associated with job-related stress and burnout (Cook, 2008; DeStefano et al., 2004).

Emergency Medical Providers

Emergency Medical Service (EMS) care, which includes first response care and transportation, is evolving to a more structured and sophisticated area of practice related, in part, to emergency preparedness infrastructure building following the events of September 11, 2001, and recent natural disasters (Office of Rural Health Policy, 2002). As a result, high-quality education is needed for EMS personnel to prepare new providers and to enable seasoned professionals, to maintain their current skills and build new scientifically based skills that incorporate technology into practice. EMS preparation is predominately focused on the pre-hospital care of adults and less attention is given to the emergency care of children. More funding and preparation are needed in the care of children (Wakefield, 2005).

Emergency medical technicians (EMTs) and paramedics held about 179,000 jobs in 2002 (Bureau of Labor Statistics, 2005), mostly in urban areas, while rural EMTs are often unpaid volunteers (ORHP, 2002). EMS units often face shortages of volunteers as traditional rural jobs, such as farming, give way to commuting to more urban-based work. Training opportunities are more limited under these circumstances and community needs may be unmet (Morton, 2003). However, the increased educational expectations and increased responsibility of rural EMS providers may also lead to EMS teams comprised of more paid employees and fewer volunteers.

Unlicensed Caregivers

Unlicensed caregivers, such as home health aides and nursing assistants, are needed in rural communities to provide essential personal-care services and assist with activities of daily living for individuals with chronic health problems and for frail older adults (NCHWA, 2004a). These populations are at risk for a lack of services or poor quality of services because they have limited income and because the services they need are often not reimbursed. Their care may be compromised because unlicensed caregivers are minimally prepared in how to provide care to older adults and because the very unstable long-term-care (LTC) workforce limits continuity of care (Leon et al., 2001; Seavey, 2004). The turnover rate among unlicensed caregivers in LTC facilities averages 71% nationally (National Commission on Nursing Workforce for Long-Term Care [NCNWLTC], 2005). Factors such as low wages and benefits, poor working conditions, little or no opportunity for advancement, physically demanding work, and low morale contribute to the loss of workers. Few rural facilities can afford the estimated cost of $2,500 per worker associated with staff turnover and which nationally exceeds $4 billion a year (NCNWLTC, 2005; Seavey, 2004). Rural older Americans use nursing home care at higher rates than urban older adults (Phillips et al., 2003) due to reasons such as unavailability of formal services, limited use of available services, availability of nursing homes, and more out-migration of family (Coburn & Bolda, 2001). But rural nursing homes are more likely to be inadequately staffed with fewer than 4.1 total nursing hours per resident day, which places residents at risk for poorer outcomes (Phillips et al., 2003). Better models are needed for delivering care and innovative financial models are needed in rural areas to incentivize service integration among acute and long-term care providers (Coburn & Bolda, 2001; Phillips et al., 2003).

Today's rural health-care workforce serves communities where physicians, nurses, dentists, and other essential providers are in short supply due to factors such as lower salaries, frequent call schedules, limited resources, and geographic isolation. However, the health-care needs of rural populations are considerable given the incidence of chronic disease, the limitation of services, and out-migration of families. The status quo of rural practice indicates that enhancing the workforce is crucial to the health of rural people.

Improving Practice

Rural communities are challenged to address the health-care workforce shortages, across disciplines, and to improve the quality of health care. This section presents ideas for improving practice as rural leaders identify their unique community needs and implement healthy community building to create integrated systems of accessible and affordable health-care services. Effective systems include an infrastructure to support interdisciplinary practice, to develop culturally appropriate recruitment and retention packages, and to support work redesign to address workforce shortages.

Changes in the prevailing norms of practice that could vastly enhance the existing rural workforce and positively influence recruitment and retention include building systems of care that include interdisciplinary practice, evidence-based patient-centered care, technology and rural–urban collaboration. Investments in technology, major changes in education including place-based education, and drastically altered reimbursement strategies that reward quality and improve outcomes are essential to move toward rural rational alternatives that attract health-care providers (Calico, 2005).

Recruitment and Retention

Rural-specific evidence-based recruitment and retention strategies are essential to building successful rural workforce programs and improving practice across disciplines. The development of health-care workforce pipelines shows promise as one effective rural strategy. Health-care providers and the educational community must collaborate to assure that quality education is provided in local schools. They must build strong math and science curricula and develop mechanisms to assure that students enroll in and succeed in these courses as a basis for health careers. Students must learn about health-care careers and health-care delivery systems. They must associate with health-care professionals and build enduring relationships as they participate in community activities and invest in their own future and the future of their communities (Bowman, 2005; Scurry, 2008). For example, school nurses and other providers who incorporate public health and population health concepts in practice might involve students in building healthy communities. Students might participate in health fairs, the provision of health screenings and education, the development of programs to prevent obesity and promote healthy lifestyles, and other initiatives that create safe and healthy communities. (Centers for Disease Control [CDC], 2008; National Association of County and City Health Officials [NACCHO], 2005).

Leaders building effective pipelines track potential health-care providers, maintain relationships, and continually connect them with the community (Bowman, 2005). For example, the University of Washington School of Medicine's collaborative program among the states of Wyoming, Alaska, Montana, and Idaho (WWAMI) involves young rural and minority students in activities that encourage an interest in a medical career. WWAMI provides several K-12 programs and follows students to affirm health career choices (University of Washington School of Medicine [UWSOM], 2008). Minority populations are untapped pools for health professions pipeline building. While diversity is not pervasive in rural areas, there is a changing landscape. Hispanics are projected to become the largest minority group in rural America (U.S. Department of Agriculture [USDA], 2005). Many Latinos are from rural areas and they are increasingly moving to rural America (Saenz & Torres, 2004). Latinos, rural African Americans, who live predominately in the south, and American Indians, who tend to reside in the west are all underrepresented in the health workforce. These rural residents are potential rural health-care providers given culturally appropriate support, counseling, recruitment, and educational opportunities.

The WWAMI program and the University of North Dakota Recruitment/Retention of American Indians into Nursing (RAIN) program are two programs that support rural workforce diversity and aim to increase the number of American Indian health professionals (University of North Dakota College of Nursing [UNDCON], 2008; UWSOM, 2008). Faculty must continue to study how to best help minority and disadvantaged students to succeed and how to integrate dedicated rural practice content in the health professions curricula (Hollow et al., 2004).

Recruiting health-care professionals from rural communities is vital, but rural communities may also attract some urban students by providing unique, structured clinical rotations or summer extern educational opportunities. Meaningful social components and comfortable living arrangements are critical to the rural educational package to successfully attract potential health care providers (Collins, 2003).

Pipeline preparation and health professions recruitment must be accompanied by effective, evidence-based retention strategies. For example, rural physician retention is associated with owning a practice, and having a reasonable call schedule. Nurse-midwives need physician collaboration and affordable insurance rates. Rural providers may feel isolated and face barriers in obtaining appropriate continuing education, but video capacity can be used to link health providers, to coach, and to support practitioners and students at remote sites to enhance their practice knowledge. Distance learning methodologies offer potential for interdisciplinary, problem-based learning; professional dialogue; and increased access to the professional literature. Practice satisfaction might be further enhanced by designing multi-provider collaborative practice arrangements to allow more provider time off and to reduce burden, workload, and call. Evidence provides a foundation for the design and implementation of successful, multifaceted recruitment and retention programs from which community leaders create and actualize their health-care vision (Cooksey et al., 2002; Fetsch et al., 2004; Hoge, 2004; NACRHHS, 2004).

Recruitment and retention packages are enhanced where the rural health-care environment is positive and the infrastructure for care is strong. In some areas, the rural health-care infrastructure and system of care is “unraveling” (Morton, 2003) as health-care priorities change toward health promotion and as reimbursement and health-care financing evolve. Technology is now crucial to efficient management, but many rural hospitals built in the 1950s lack technological capacity (Morton, 2003). Future infrastructure requires wired facilities along with appropriate technology and equipment. A well-prepared information technology staff is essential to assist health-care professionals to integrate patient care records, decision making, and billing components, and to incorporate a population-based system of care to manage chronic illnesses and reduce health disparities (Calico, 2005; Morton, 2003; Wakefield, 2005).

Recruitment and retention of unlicensed personnel receives little attention, despite the aging population and the high turnover among LTC nursing personnel. So improving the care environment through mentoring, increasing wages and benefits, and effecting standard training policy is crucial to retaining staff (Mockenhaupt et al., 2006; Seavy, 2004).

Family physicians, nurses, and other rural providers are committed to caring for groups of people across the lifespan with a variety of illness and wellness needs. Unique provider/patient relationships, more professional autonomy, and a lower cost of living are all priority aspects of rural practice to those who choose to serve in rural America (Rabinowitz, 2004). Evidence is becoming more available to inform leaders on the types of recruitment and retention activities that rural communities must embrace to enhance the workforce. New models of practice, better facilities, technology, diversity, rural practice preparation, and pipeline building are vital components of a dynamic rural workforce and quality health care.

Education and Training

The current status of health professions education is presented in this section. Curricular content gaps and the Institute of Medicine (IOM) recommendations for improving health professions education are addressed. The education and training needs of unlicensed personnel are acknowledged.

Current Status

The health-care workforce is educated in discipline-specific programs according to institutional and professional organizational standards, regulating bodies, and the discipline's unique culture and history. Health professions education programs differ in structure, entry levels, program length, clinical training sites, and governance. These inconsistencies create complexity in designing new interdisciplinary curricula and clinical practices. The majority of health-care professionals are educated in urban academic settings where students are socialized into specialty care by specialty faculty and preceptors. Academic centers value funded research and clinical activities and educational methods receive less emphasis (Greiner & Knebel, 2003). As a result, there may be little opportunity for interdisciplinary education, leadership development, or population health experience to prepare graduates to practice in today's complex health-care environment. Graduates may not internalize the notion of lifelong learning or the concepts of change and the responsibility to improve the quality of care through process and systems of care (Berwick, 2003). They may also have little understanding of cultural competence or health literacy and the implications of that knowledge for serving rural and underserved populations (Kohn et al., 2000; National Council of State Boards of Nursing NCSBN, 2001).

Gaps in Health Professions Education

Rural health-care content and rural practice opportunities are provided by only a few educational programs. Therefore, graduates of health professions programs often have little knowledge of rural community health needs. There are notable exceptions, however, such as the West Virginia University Rural Health Partnership

Education Program (West Virginia Rural Health Education Program [WVRHEP], 2006) where all health-care students complete rural clinical rotations and the Jefferson Medical College of the Thomas Jefferson University Physician Shortage Area Program (PSAP). The focus of the PSAP program is to seek and selectively admit to medical school, rural students who commit to practice family medicine in a rural area after graduation (Rabinowitz, 2004). There are data to support that "Educational strategies and institutional strategies can influence graduates to select practice sites where clinicians are particularly needed" (Edwards et al., 2006, p. 69), such as in rural or underserved areas. Graduates from a rural background or from a rural-focused educational program are better prepared for the realities of rural practice and rural living. They may be more likely to ascertain rural health needs, remain in rural practice, and to continue lifelong learning to improve their practice (Edwards et al., 2006; Daniels et al., 2007).

Seasoned clinical faculty and health-care professionals may lack informatics, computer, or other technology skills necessary to access essential information to improve their teaching or practice skills. Rural providers may have limited educational exposure to informatics content or technology (Carty & Rosenfeld, 1998). Rural providers operate within narrow financial margins and they often lack the infrastructure to develop electronic patient records and integrated information systems. Rural patients may not have access to the latest health-care technology that is available in urban areas (Kennedy, 2007).

The U.S. Census Bureau (2000) indicates that 15% of the US population will be over 65 years of age by 2015. Health professionals are woefully unprepared in their educational programs for the complexity of care that will accompany this large population of older adults (Greiner & Knebel, 2003). Kovner et al. (2002) reported that only 23% of baccalaureate nursing programs and fewer than 10% of medical schools required students to take a geriatrics course. Schools and agencies must invest in geriatric education and clinical training for health-care professionals. Interdisciplinary research is needed to develop new knowledge regarding the care of older adults that can be translated into new clinical practices (Pincus et al., 2007). Unlicensed caregivers receive minimal preparation in how to provide care for older adults and there is a lack of consistency across settings in the training they receive. As the US population ages, more unlicensed and informal caregivers will be called upon to provide care; and their educational needs must be addressed to ensure quality services to care recipients (Buckwalter & Davis, 2004; Mockenhaupt et al., 2006).

Cultural competency and health literacy content are also lacking from health professions education. The Sullivan Commission report (2004) and other reports (Greiner & Knebel, 2003) address the need for health professionals to receive cultural competence and health literacy training, particularly in relationship to the disproportionate numbers of minorities in the health professions.

Lifelong learning is another gap and a particular challenge for rural providers who lack coverage for time away, and limited access to technology. These challenges limit professional communication, access to professional literature, and distance learning. As a result, practitioners may not be adequately prepared to identify and synthesize information for evidence-based practice, to apply best practices, or to improve quality.

In summary, health professions education varies among disciplines and there is often little opportunity for interdisciplinary collaboration and lifelong learning. Educational gaps are evident in information technology, culture, geriatrics, patient safety, quality improvement, and rural practice preparation. There are also IOM recommendations that could potentially create sweeping changes in health professions education and continued competency to meet patient needs and improve care (Greiner & Knebel, 2003).

Improving Education and Training

The Institute of Medicine report on health professions education participants (Greiner & Knebel, 2003) challenges how health professionals are educated and provides recommendations for changes. The report recommends that health professionals should be prepared for five core competencies: (1) provide patient-centered care, (2) work in interdisciplinary teams, (3) employ evidence-based practice, (4) apply quality improvement, and (5) utilize informatics (Greiner & Knebel, 2003). These recommended core competencies are important to improving the quality of care in rural communities.

Patient-Centered Care

Rural patient-centered care is culturally appropriate to the patient and what he/she values in the patient/provider relationship. The patient's health beliefs and health literacy are integral to patient/provider shared decision making and care management (CFRHC, 2004; Green-Hernandez, 2006). More broadly, patient-centered care involves community engagement to determine the local health-care needs, plan systems of care, and implement quality-focused community care models such as population-focused care (CFRHC, 2004).

Interdisciplinary Teams

Health professions education can be improved by helping health professionals learn to work in interdisciplinary teams (Greiner & Knebel, 2003). Interdisciplinary education is a collaborative process among health-care stakeholders to provide interdisciplinary clinical and didactic education and training (The Advisory Committee on Interdisciplinary, Community-Based Linkages [ACICBL], 2005). Proponents of interdisciplinary education encourage the use of problem-based learning and recommend that faculty be rewarded for implementing interdisciplinary learning and overcoming the associated educational barriers (Hall & Weaver, 2002).

Lawrence (2002) contends that teams of health professionals are needed to consolidate the scattered pieces of the current health-care system in order to build integrated systems of care and to provide quality care. Rural health professionals have a high propensity to work in interdisciplinary teams to comprehensively address chronic illnesses and health promotion population needs, to decrease acute care patient length of stay, and to provide safe care across care settings (CFRHC, 2004; Clark et al., 2002; Greiner & Knebel, 2003; HRSA, 2000).

Evidence-Based Practice

Health professionals who are prepared in and employ evidence-based practice are disciplined in data collection, best practices, and professional guidelines for patient care decision support. These skills enable care providers to use evidence and best practices in the context of their provider expertise and the patient's values to assure quality care. The Internet is a key access point for evidence-based practice information resources such as the Agency for Health Research and Quality (AHRQ) and the Cochrane Collection. However, their use may be limited by the lack of Internet infrastructure or support. There may also be a lack of clinical studies relevant to rural practice and. studies conducted in tertiary care settings may not have clear application to rural care (CFRHC, 2004).

Quality Improvement

Health professionals are accountable for the use of health-care resources and for the effectiveness of the processes of care. Therefore, rural providers must use basic concepts of quality improvement and population health principles to improve access to high-quality health care for all rural Americans (Calico, 2005). Small rural communities have an excellent opportunity to redesign and test new quality care systems. The HRSA Health Care collaborative models (HRSA, 2005) have great potential for implementation in rural communities because the models are interdisciplinary and patient-centered. The collaborative models incorporate quality measurements and use improvement tools to achieve better outcomes. While some health-care quality improvement designs and measurement may vary between urban and rural communities, due to low volume of services and the quantity of services provided, other measurements should not differ. For example, fast and effective acute myocardial infarction (AMI) care must cross all settings of care. AMI care is a major component of the Institute for Health Improvement's (IHI) *100,000 Lives Campaign that* encouraged hospitals to adopt six evidence-based interventions to improve care and save lives (Institute for Health Improvement [IHI], 2005). Now the 5 Million Lives Campaign is in place (2006–2008) to protect patients from five million incidents of harm (IHI, 2008).

Quality initiatives, such as AMI, are consistent with the IOM definition of quality of care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM, 1990, p. 4). Rural quality of care community priorities include: (1) using an integrated approach to address personal and population health needs; (2) developing a strong health-care quality improvement support structure to assist providers; (3) enhancing the human resource capacity of health-care professionals and expanding opportunities for rural residents to learn how to actively engage in improving their health and health care; (4) assuring that rural health-care systems are financially stable; and (5) investing in an information and communications technology infrastructure (CFRHC, 2004).

Addressing community priorities to improve quality begins with providers who measure quality and use improvement tools as an integral part of their delivery of care (Calico, 2005). Berwick (2003) contends that in order to improve the quality of care "we will have to re-envision, and largely re-train the health care workforce, so that they can become citizens in the improvement of their own work" (p. i3). Care improvement processes can be taught in educational programs and continuing education contexts, particularly through interactive clinical experiences and service learning projects and using health disparities collaboratives. Quality improvement cannot be done in isolation and, therefore, skills in collaboration, interdisciplinary team work, and communication are essential curricular components for educational programs.

Utilize Informatics

Future education systems will maximize technology to deliver information at the point of care and at the point of learning for rural students. Progressive learning methodologies that involve students in the integration and application of content are replacing the traditional lecture method (Wass et al., 2001) and the classroom is being transformed through distance learning, virtual and simulation learning, and clinical skills-testing techniques (Greiner & Knebel, 2003).

Telehealth is a viable alternative for service delivery in some rural areas, underserved areas, and even school systems. Consumers accept technology to monitor health and to decrease travel to access care. Tools such as videophones and interactive computer networks are useful to individualize and deliver quality care and promote cost-efficiency. Students benefit from these delivery models as well, and are better prepared to use and advocate for telehealth in practice (Buckwalter et al., 2002).

Other Educational Gaps

Rural communities can benefit from a number of ongoing initiatives to educate health-care professionals and unlicensed providers on how to care for older adults. The John A. Hartford Foundation, the Robert Wood Johnson Foundation, and the American Nurses Association support initiatives for health-care professionals to become better informed in geriatrics and to improve the care of older adults.

Rural workforce educational content and practica to prepare culturally competent practitioners might address the social, economic, cultural, and political landscapes of rural communities. Actual and virtual immersion in rural life and industries such as farming, mining, and tourism are methods that hold merit (Collins, 2003). Rural interdisciplinary case studies may also be useful to advance critical thinking about rural population care. Health professions' programs that produce a high percentage of graduates who work in rural areas and serve underserved populations should be continued (Edwards, et al., 2006; Rabinowitz, 2004; WVRHEP, 2006).

The recommendations of the IOM committee for reforming health professions education were presented in this section. Methods were discussed to improve education and training and prepare graduates for quality rural practice with diverse clients.

Research

Research studies encompassing the rural health-care workforce are described in this section. The next section provides an overview of the research being conducted and demonstrates gaps to be addressed in future studies.

Current Status

Rural health-care workforce studies are limited in scope and impact due to factors such as the use of varied research designs and methodologies that inhibit the comparison of outcomes. There are also few health-care education studies that evaluate education over time or that link curriculum changes to patient outcomes (Greiner & Knebel, 2003). More data are available on physician providers than any of the other professions, yet data are still lacking on the practice areas of physicians and other health-care professionals who benefit from federal scholarship and loan programs to promote primary care in rural and underserved areas. National Health Service Corps (NHSC) data and outcomes are more readily available than data for other programs (Pathman et al., 2000).

Studies that investigate the recruitment and retention of physicians to rural areas are probably the most numerous of the rural workforce studies. While the study variables differ among researchers, findings consistently demonstrate the effect of a rural upbringing in building and retaining the rural workforce (Bowman, 2005; Daniels et al., 2007; Looney et al., 1998; Pathman et al., 2004; Rabinowitz et al., 1999). The replication of studies to affirm findings over time and the use of consistent operational definitions and measurement tools is still lacking. There is also a lack of data regarding the practice patterns of other interdisciplinary team members such as social workers and physical therapists.

Registered nurses comprise the largest number of health-care workforce providers, but data are limited on the actual number of RNs practicing. US rural and urban

RN characteristics were recently compared in a study. The findings indicate that urban and rural RNs have similar demographics; however, rural RNs are more likely to hold a diploma or an associate degree and to have lower incomes than urban RNs. Rural RNs are more likely to work in public/community health and urban RNs are more likely to work in hospitals (Skillman et al., 2006). Another study investigated how the public views nurses and nursing careers. Nursing careers were viewed positively and nurses were held in high esteem by study participants. The profession must captivate on these findings to effect a national nursing workforce plan to assure an adequate supply of nurses for the future (Donelan et al., 2008).

Olade (2004) studied the use of evidence-based practice among rural nurses and found that only 20.8% of participants reported using research evidence in their practice. Nurses who used evidence were more likely to have a bachelor's degree and to use research in the areas of pain management and skin care. The lack of nurse researchers and role models in rural practice, as well as financial and budget constraints limits research utilization among rural nurses.

There is a dearth of research on the rural geriatric health-care workforce and geriatric work settings. However, Kovner et al. (2002) found that patients cared for by nurses educated in geriatrics were less likely to be restrained or readmitted to a hospital. Since rural communities have high numbers of older adults, data are needed on the best geriatric workforce training models, safe staffing ratios, and critical quality improvements (Kovner et al., 2002).

Buckwalter & Davis (2004) made significant contributions to the body of knowledge in elder caregiving and the associated challenges in rural communities where family, friends, and neighbors provide extensive caregiving. Many caregivers lack care assistance because they may be unaware of available services or they question their eligibility for services and other reasons. Caregiver input is key to developing successful training and support programs that meet the particular needs of rural caregivers in the context of their social networks.

Researchers and policy makers have inadequate information on the magnitude of unmet need or the amount of care that is already provided at no or low cost (Larson et al., 2003). Also, little information is available on how rural people living with chronic illnesses view their quality of care (Weinert et al., 2005) or how they self-manage symptoms such as pain (Vallerand et al., 2004).

The WWAMI Rural Health Research Center (2006) studies provide evidence to support rural workforce and/or care delivery decisions. Researchers are investigating the contributions of J-1 Visa IMGs to the rural physician workforce, rural physician supply, and the implications for rural underserved areas with fewer medical students pursuing careers in primary care. Other studies are focused on identifying educational programs that prepare rural physicians, and on rural residency training of family physicians (WWAMI, 2006).

Researchers at the University of Pittsburg and West Virginia University are collaborating in an unusual approach to oral health research by investigating the genetic and environmental risk factors that might affect oral disease. Since the people of Appalachia have an unusually high proportion of oral disease, this comprehensive study of immune function as well as economic, behavioral, and environmental factors, is important. It holds promise for new approaches to preventing oral disease and promoting better health among rural populations (Hanson, 2006).

There are limited rural workforce research studies, and more data are needed on the practice patterns across disciplines, on the geriatric workforce and family caregiving. Additional studies on rural health care and new ways to treat chronic health conditions would benefit rural health.

Research Needs

Rural specific research regarding the workforce or rural health is limited and continued study is necessary. Shortages are occurring across disciplines, but data to support shortage reduction programs are limited. Some policy initiatives address the nursing shortage, but additional studies are needed to determine how these initiatives affect rural practice. The trend away from primary care as a career choice for physicians also merits close examination. Lack of definitive solutions to the shortage of dentists and pharmacists suggests that research should be conducted on new models for delivering dental and pharmacy services in rural areas.

Rural EMS systems have limited capacity and resources and staff are often dedicated volunteers who also hold other positions for their livelihood (ORHP, 2002). Therefore, research is needed to determine how to build and sustain excellent EMS system capacity and to deliver improved emergency services in rural settings.

The Institute of Medicine report *Quality Through Collaboration: The Future of Rural Health* (CFRHC, 2004) is the impetus for quality initiatives throughout rural America. It is imperative that rural quality data be collected to improve practice. Some service-volume outcome studies are needed, but other studies must expand beyond urban–rural comparisons, for example, to the range of services needed. Data are needed on what services are reasonable and what might be available through technology or through building systems of care (NACRHHS, 2003),

Population-focused care models ought to be implemented and tested in community settings. These models integrate public health and primary-care concepts to promote and improve the health of a defined community/population, as opposed to individuals, by assessing the population need and designing need appropriate systems of care (Donaldson et al., 1996). For example, more data are needed on the implementation and outcomes of rural health-care collaboratives (Calico, 2005).

More research is needed on how telehealth is used in rural practice, such as in delivering behavioral health services and consultation to rural providers, as well as the economic and health-care implications for telehealth service delivery. More data are also necessary around rural patient safety issues, to identify where errors occur and how they can be prevented, especially related to medication errors (Casey et al., 2005; NACRHHS, 2003).

The research section provided an overview of the current rural research and what is needed. Existing physician workforce studies must be replicated to affirm findings over time and to use consistent operational definitions and measurement tools.

Other rural provider data are critical for workforce enhancement. Gaps in patient-focused and population-focused care, rural services, telehealth, quality, and patient safety are also recommended areas for future studies.

Policy

Rural health-care workforce policy is addressed in this section. There is a focus on policies that affect workforce development because they impact the work environment, quality of care, and access to care.

Current Status

Public policy that results in monetary support for health professions education and training of primary-care providers, nurses, dentists, and mental and behavioral health-care professionals, is critical to building and retaining the rural workforce. Many federal programs aim to reduce health disparities by increasing workforce diversity and by promoting geographic distribution of health-care providers. Award selection criteria often give considerable weight to the recruitment and retention of underrepresented minorities and disadvantaged students into health professions programs. These programs drive practice distribution by paying tuition expenses, or repaying, or forgiving student loans for graduates who will practice with underserved or rural populations. Other education and training programs support infrastructure development to grow educational programs, prepare faculty and preceptors, implement simulation and distance learning, and create learning communities that address cultural diversity and care of the underserved (Advanced Education Nursing Program [AENP], 2005).

The NHSC program increases the numbers of providers practicing in underserved areas through scholarship and loan repayment programs. Similarly, the J-1 Visa Program, described in the practice section, allows IMGs to remain in the United States in exchange for practicing in an underserved area (Pathman et al., 2000; Ricketts, 2005).

The Quentin Burdick Rural Interdisciplinary Team Training Program represents a policy approach to enhance place-based practice (Ricketts, 2005). The program promotes the use of new and innovative methods, including interdisciplinary practice models, to build the community of rural practitioners and improve the quality of care. It also supports the conduct of rural health-care research and the recruitment and retention of rural providers (Quentin N. Burdick Rural Program for Interdisciplinary Training, 2005). The program ended in FY 2005, but program outcome data may provide useful information for future rural program development.

The Area Health Education Centers (AHEC) programs demonstrate policy implementation regarding geographic distribution of health-care providers (Ricketts, 2005).

AHECs are "academic-community partnerships that train health care providers in sites and programs that are responsive to State and local needs" (Area Health Education Centers [AHEC], 2006, p. 1). AHEC programs provide continuing education to more than 330,000 practitioners per year (Ricketts), support minority students in science education, and arrange housing for students receiving clinical training in rural sites.

Rural entities have a long history of federally allocated resources for rural health-care workforce development (Ricketts, 2005) and for the improvement of care, but some continue to believe that policy favors urban care and that rural needs are often shortchanged. For example, the Medicare program has for some time paid less to rural than to urban providers for the same service (Williams & Cutchin, 2002). Also, market-driven policies focused on cost containment and economic efficiencies are often misaligned with rural needs and result in fragmented care systems (Morton, 2003). Policy support for rural health-care providers is seen in the Critical Access Hospital (CAH) funding within the Rural Flexibility Program. This program aims to "stabilize fragile small rural hospitals to support access to care for Medicare beneficiaries" (Calico, 2002a, p. 1). The program helps build rural health-care systems and maintain essential health-care services in rural communities.

Some electric co-ops provide affordable broadband Internet access to small rural communities as value-added services where broadband is not otherwise available. A policy ruling by one state supreme court that electric co-ops cannot provide any service other than electricity (Wesslund, 2006) now limits rural access to dial-up Internet. This policy severely restricts access to resources and educational opportunities for rural providers.

Policy Improvement

The Rural Policy Research Institute (RUPRI) Health Panel was established to provide science-based, objective policy analysis to federal policy makers (Rural Policy Research Institute [RUPRI] Rural Health Panel, 2006). In a recent publication, RUPRI panel members recommended federal policies to improve patient safety and rural health quality. The principal recommendation was to create a Congressional authorized Rural Health Quality Advisory Commission. The Commission would develop a national plan for rural health quality improvement, design demonstrations to test quality improvement models, and make performance reports to Congress (RUPRI, 2006).

The RUPRI panel also made policy recommendations in four major program areas that address rural health workforce development, infrastructure building, rural health-care finance, and information technology implementation and utilization. If the policy recommendations are implemented, Title VII and Title VIII programs, which integrate rural clinical educational experiences and teach the IOM recommended core competencies for health professions education (Greiner & Knebel, 2003), would receive preferential funding. Infrastructure development recommendations would support quality improvement and organizational culture change as well as rural-specific practice protocols, measurement, and reporting. Financial recommendations would encourage rural payment adjustments for essential services, assistance for data collection and public reporting, and evidence-based rural benchmark development. The information technology focus would promote policy to improve access to information technology and adapt information systems to rural health provider scale (RUPRI, 2006).

The RUPRI also recommends allowing Medicare, managed care organizations, and other payers to provide financial incentives, such as higher reimbursements, for facilities that employ geriatric specialists to improve the quality of care to older adults. In addition, others suggest that financial incentives be made to rural providers for serving high numbers of low-income patients.

Policies are needed that reach beyond current practices and address social and economic issues that perpetuate poor health in rural areas. Policies must enable basic health promotion and prevention care for all people and support population health if we are to achieve the Healthy People 2010 goals of increasing health quality and the number of years of healthy life, and eliminating health disparities (Morton, 2003).

Summary

The current status and future needs related to workforce issues in rural caregiving were presented in a framework of practice, education, research, and policy development. Rural Americans face challenges in all of these areas to achieve high-quality health care. Therefore, rural Americans across the United States are blending their talents to develop healthy communities and quality health-care systems and, ultimately, to enhance the overall quality of life. Community partners are designing unique solutions to their specific problems and needs. For example, one program employs navigators to help the uninsured or underinsured navigate health-care systems and another program enlists and enables health-care providers to give free care to local residents (Rowley, 2004).

The rural workforce shortages across disciplines continue, but a number of programs and policies hold promise for enhancing the rural workforce and improving rural health care. Progress is evident in interdisciplinary education and practice, technology use, and in quality improvement demonstration projects. As rural-specific research informs policy decisions and practice, the workforce is enhanced, high quality of care is provided, and the people of rural America are healthier.

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Chapter 9
Telemedicine: The Use of Information Technology to Support Rural Caregiving

Peter Yellowlees, Thomas Nesbitt, and Stacey Cole

Nowhere is information technology potentially more critical in the redesign of the health-care delivery system than in rural and frontier areas (Institute of Medicine, 2004), where it has the potential to dramatically change the way caregiving occurs. We are moving from health-care systems aimed at providing episodic institutional care for the treatment of illnesses to information-based systems seeking to promote increased consumer and caregiver involvement in the prevention of illness across the life span. Rural and frontier providers and caregivers are often faced with the need to provide a broad scope of practice with regard to medical condition, age, socioeconomic level, culture, and gender (Rosenthal & Fox, 2000). This occurs in an environment with far fewer specialty consultants and ancillary resources, and where a higher threshold for referral to larger centers may exist because of distance and economics (Rosenblatt & Hart, 1999).

A more rational system of care can be facilitated using currently available advanced information and telecommunication technology, including electronic medical records, electronic information retrieval, decision support for providers, remote monitoring, telemedicine, remote language and cultural interpreting, and even distance robotic surgery. This is more than the simple use of technology; it is successful and sustainable when there is a seamless merger between technological, human, and organizational factors – e-health (Yellowlees, 1997).

Where rural residents and caregivers in their daily lives have access to high-quality health information for self-directed health-care decisions, e-health seems feasible (Mandl et al., 1998). Easy communication with physicians by secure multimedia e-mail or personalized patient health portals allows for physician-supported home care. Patients and families may be directed by their physician to high-quality information sources to help them understand disease and treatment processes. Patients

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can keep a personal health record that is also available to health-care providers. Patients with chronic diseases can also be cared for at home through caregiver support and the use of monitoring devices that connect with their providers' offices. Health-care providers would be able to assist with day-to-day management of conditions such as diabetes, asthma, and hypertension.

Access to Health Information

Practice

For most people, the majority of health-related behavior is self-directed. For people in rural areas where access to health care is more limited, self-care may be even more important. In the past, information for these self-directed health-care decisions has traditionally come from friends, family, and newspapers and magazines. More recently, television has provided major sources of health information from public health campaigns, medical dramas, and direct marketing from pharmaceutical companies. For patients with specific diagnoses, health information has often been exclusively obtained through a personal physician, with limited opportunity to access second opinions. The Internet has also become a major source of health information for both patients and physicians (Nesbitt et al., 2002). Patients with chronic health conditions or disabilities are even more likely to turn to online resources for health information (Fox, 2007).

Research on Access to Personal Health Information

With the advent of the Internet, access to health information has improved dramatically (Nesbitt et al., 2002). The 2006 Pew Report noted 60–70% of Americans now have home computers (Fox, 2006). The online population continues to increase showing 77% of Americans who now use or have access to the Internet (The Wall Street Journal Online, 2006). Five major demographic dimensions continue to be associated with less Internet use: minority race, low income, low educational attainment, older age, and rurality (Horrigan, 2008). Broadband growth among these groups of concern appeared generally strong over the last year; however, each group still lags behind the larger population. Broadband adoption for those over 50 grew 26%. Low-income ($20,000–$40,000) broadband penetration grew 24% in 2008, resulting in 45% of this group now having broadband Internet access. Yet, households with incomes under $20,000 showed the only decrease in broadband adoption reported, with 25% adoption compared with 28% adoption in 2007. Rural areas still lag behind urban and suburban areas for broadband adoption with only

38% broadband adoption compared with 57% and 60% adoption, respectively, by urban and suburban areas (Horrigan, 2008).

A 2006 Harris Interactive Poll reported that 80% (136 million) of adults in the United States have used the Internet to access health information, a 16% increase over the previous year (Harris Interactive, 2006). Data on the percent of Internet users who search for health information vary dramatically. Baker and colleagues (2003) reported that 40% of Internet users looked for advice or information about health or health care, and a third of these users reported it affected a health-care decision, other reports have suggested that Internet use for health-care purposes is much higher (Baker et al., 2003). The Boston Consulting Group reported that 80% of the 10,000 patients surveyed said they had searched for health-related topics (Boston Consulting Group, 2003). Patients with the most severe and chronic illnesses appeared to have a more positive experience with online health information. Patients with chronic illnesses incorporate the information they discover online into their health-care decisions more frequently than the rest of the population (Fox, 2007). Some reviews have noted that caregivers tend to look for health information more commonly than patients (Yellowlees, 2001). A research project by the California HealthCare Foundation estimates that of health-care consumers, family caregivers make up 80–90% of online site visitors for long-term care decision support (California HealthCare Foundation, 2008).

A number of authors (Hsiung, 2002) have described the difficulties in ascertaining the quality of information available for patients on the Internet. For health-care consumers, using search engines to find health-care information is time consuming and yields a low percentage of relevant sites. As websites become more personalized and search engines become more powerful and intelligent, these issues will be addressed with the development of better quality standards.

Electronic Patient and Caregiver Support Groups

Practice

In rural areas, there is often not a critical mass of people with a particular chronic disease to form a support group (Lieberman et al., 2003). For less common and more serious diseases, rural areas frequently lack professionals to provide oversight to a support group. As a result, electronic support groups have developed for many diseases. Nearly every chronic illness has several online support groups or chat rooms that may or may not be supervised by a medical care provider or “expert in that area of expertise” (White & Dorman, 2001). In many urban areas, patients attend support groups sometimes hosted by their physicians specializing in their chronic illness, thereby providing structured reinforcement and collaborative support with peers. Further, support groups frequently facilitate the self-management of chronic diseases for patients and caregivers.

Research on Electronic Patient and Caregiver Support Groups

There has been little research conducted on the benefit of either sponsored or un-sponsored electronic support groups specific to rural patients and caregivers. However, within the United States every day 3 million people use electronic support communities (Sands, 2002). Liederman & Morefield (2003) performed a clinical trial for a breast cancer support group delivered to individuals through the Internet to compare pre-group and post-group scores on several criteria, including depression and pain ratings. The group consisted of 32 women, 49% of whom lived in a rural or small town. The finding showed a statistically significant reduction in depression, although pain ratings remained the same. Six to seven percent of the women reported being helped by the electronic support group (Lieberman et al., 2003).

Pierce and colleagues evaluated Internet-based education and support interventions for rural caregivers on the basis of satisfaction (Pierce et al., 2004). Hill and colleagues (2004) evaluated online medical support, including e-mail, conversations, and resources for a group of rural women with chronic illnesses. Interactive options were ranked as having the greatest importance (Hill et al., 2004). Other research in this area includes a study of a support group for rural women with Diabetes (Smith & Weinert, 2000) and a larger study by the Women-to-Women Project (Weinert et al., 2005). Electronic support groups will likely continue to grow as users become more familiar with computers and as those who grow up with computers begin to age.

Provision of Provider-Directed Educational Materials

Practice

Providers develop educational materials specifically for individual patients, groups of patients, or communities. Such informational sources that are electronic are now usually on the Internet or distributed on compact disks. They tend to be very focused and, increasingly, they are “prescribed” as part of a treatment plan. For example, nutrition programs for obesity that include patients’ weights being monitored by themselves and their physicians on the Internet, essentially become full-scale disease management programs. Other disease management programs are rapidly evolving for illnesses such as diabetes, cancer, depression, and heart disease. Such programs could provide personalized, tailored solutions to patients from rural, remote, and underserved populations with chronic disease conditions.

Research on Provider-Directed Educational Materials

Although provider-directed education materials are common in all forms, there is little published research on the effectiveness of these materials. In regard to decision aids, only 31 of 221 educational sources by O’Connor et al., (2006) had been tested in randomized clinical trials. Decision aids have been found to be of great support for patients.

In clinical trials, media including interactive software and web applications have been found to reduce decisional conflict and indecision. In the review by O'Connor et al., many of the 221 decision aids were available on the Internet (O'Connor et al., 2006), making them available to anyone with a computer, regardless of geography. Shaikh and Scott (2005) evaluated websites that provided information on breastfeeding. Whereas the information appeared to be accurate in most cases, the authors suggested that health-care providers review the material on the Internet and make recommendations to websites they feel represent credible information (Shaikh & Scott, 2005). Other studies evaluate electronic databanks of information provided to patients (Johansson et al., 2004), electronic storyboards for patients (Kisak & Conrad, 2004), and video modeling (Krouse, 2001). In the near future, online or DVD-based virtual reality simulations may also provide effective modeling for patients undergoing significant procedures or to provide patients with information about their health conditions. Further modeling may allow patients to select different scenarios or options for virtual medical care, which may assist them with their real-life medical choices.

The Ability to E-mail Directly to Physicians

Practice

In a 2003 survey, it was reported that only 6% of US patients used e-mail to contact their physician (Baker et al., 2003). However, e-mail is increasingly being used as a direct form of communication between patients and their regular physicians, not only to schedule appointments (Anand et al., 2005) and check test results, but also in areas such as mental health for actual therapy. The Journal of the American Medical Informatics Association has published guidelines for the use of e-mail for patient-provider communication (Kane & Sand, 1998). For patients and caregivers, particularly those some distance from a physician's office, e-mail offers significant convenience. In a recent study by Liederman, it was reported that "a web-messaging system was preferred over phone calls by both providers and patients for the communication of non-urgent problems" (Liederman & Morefield, 2003). In addition, e-mail consultations are increasingly being offered by commercial companies such as Partners Health Care (Parker-Pope, 2003), often at very inexpensive rates. The American College of Physicians Medical Service Committee has supported the use of e-mail with patients and, in a policy paper in March 2003, cited numerous surveys indicating that physicians and the public are using computers and the Internet more every day, and that the major barriers to physicians using e-mail consultations to provide care to their established patients is the "lack of reimbursement for this service by Medicare and many private payers" (American College of Physicians, 2003). The paper promoted the importance of paying for e-mail consultation services with established patients noting that "all parties will benefit: physicians can spend more time serving their patients, yielding a happier and healthier patient population, while the government and private insurers save money by averting sometimes costly and unnecessary face-to-face office visits" (American College of Physicians, 2003).

Research on E-mail Contact with Physicians

Some research is beginning to be conducted on e-mail communication by providers in rural areas; however, much more research is being conducted in urban and suburban areas due to more financial resources and larger medical centers, which have integrated technology more quickly than small rural practices. Some issues related to security and reimbursement/compensation have limited the amount of e-mail communication between patients and providers for health-care purposes (Komives, 2005). One study evaluated Secured Web Messaging used by primary-care providers to communicate with patients in suburban areas. This study showed that 67.7% of web messages were related to “medications, …other medical questions,” and “general chronic symptom or health condition,” Sixty-five percent of providers receiving greater than two e-mails were “very satisfied” or “somewhat satisfied” with Secured Web Messaging (Liederman et al., 2005).

Houston and colleagues studied early adopters of e-mail communication with physicians using an Internet-based survey and telephone follow-up. E-mail users were twice as likely to be college educated, younger, less likely to be from an ethnic minority, and more likely to be in fair or poor health (Houston et al., 2004). Anand and colleagues evaluated the content of e-mail interactions between pediatricians and 54 parents, which resulted in 81 e-mails leading to 9 visits, 21 phone calls, 4 subspecialty referrals, and 34 communications related to medications, 11 related to administrative tasks, and 1 regarding radiograph. E-mail content included non-acute patient-related questions ($n=43$), requests for medical updates ($n=20$), subspecialty evaluations ($n=9$), and administrative issues ($n=9$). Ninety-eight percent of patient respondents reported their experience with e-mail communication as “very good” or “great” (Anand et al., 2005). Whereas e-mail appears to be a ripe area for physician–patient communication, e-mail security remains one of the primary concerns. Web-based tools, which have similar functions to e-mail, are a secure alternative to e-mail communication and may play a much greater role in the future of electronic communication between patients and providers. Better reimbursement for such communication would likely provide an incentive for more providers to use e-mail communication for patient care and follow-up.

Development of Personal Electronic Medical Records

Practice

Shared paper records have been used for many years and in particular for home care. The records are traditionally maintained at the patient’s home, where nurses and doctors can write in them, and patients and caregivers can see them. They are particularly valuable in hospice home care and in geriatric medicine. Similar shared records have also been used for antenatal care and for childhood immunizations. There is obvious benefit of having these records in an electronic form, allowing copies to be easily sent to appropriate parties, especially in rural areas where isolation adds an extra incentive for their use (Jones, 2003). With effective audit trails and measures to assure privacy and confidentiality, the development of patient-owned or patient-and-provider-shared records would be of particular value in rural areas. An example of the benefits of shared records was reported in the Wall Street Journal in 2002, where it was cited that the Geisinger Health System in Pennsylvania was making records available to patients and their families, allowing them to check "lab results and medications…order prescription refills, and make appointments" (Rundle, 2002).

Research on Personal Electronic Medical Records

Literature searches returned little research on personal electronic medical records; however, the body of literature on the topic continues to grow. The use of personal electronic medical records for sharing critical patient data for patient treatment in the event of a disaster has been a particularly strong area of growth.

Only a limited number of health-care providers have implemented electronic health records that are accessible to patients. Kaiser Permanente has teamed up with Microsoft's HealthVault™ to provide a service that allows patients to store, manage, and share medical information selectively using the Web (Lawton, 2008). Google™ also provides a health service called Google™ Health that allows patients to upload and import data from pharmacies and labs, as well as enter health information themselves (Vascellaro, 2008). Online privacy and security issues, in addition to only 14% of medical practices in the United States using electronic records, has hindered the adoption of personal health record services (Lawton & Worthen, 2008). Many of the companies providing personal online health record services are not "covered entities" (health-care providers, health insurers, or health-care clearing houses), and therefore are not subject to the Health Insurance Portability and Accountability Act (HIPAA) which governs specific standards for handling health information, including disclosure, marketing, and access restrictions (Knight, 2008). While many online personal health record services are not subject to HIPAA, most have put in place their own set of privacy and confidentiality guidelines in an effort to reassure health-care consumers.

Those practices that provide personal electronic medical records are typically part of larger health systems, which have limited rural presence. Some things can be learned, however, from more general research on the use of electronic medical records. Several groups have advocated the introduction of personal electronic health records; however, there still remain few systems with patient accessibility.

Earnest and colleagues performed a randomized controlled trial that provided patients with congestive heart failure access to their own medical records (Earnest et al., 2004). Fifty-four patients used the System Providing Patients Access to Records Online (SPPARO) to access their medical records online using a password and login. Focus groups were conducted after the trial to obtain feedback. Patients felt (a) they were able to understand the process of medical care better, (b) they were able to use their reports for memory reinforcement, (c) felt they had increased participation in their health care, and (d) streamlined the flow of information. Ertmer and Uckert (2005) also found positive effects on patient empowerment through electronic health records. Furthermore, access to personal medical records was found to improve patient adherence to medical advice (Ross et al., 2004).

One concern was that patients found the medical jargon difficult to understand; however, most compensated by using medical dictionaries and online references (Earnest et al., 2004). Hassol and colleagues found that while patients were mostly positive, there were concerns over confidentiality and patients discovering abnormal lab results electronically (Hassol et al., 2004). Whereas many new electronic health record systems provide the ability to offer patients electronic access to their health records, few health-care providers have implemented this aspect of their electronic health record systems. As health care moves toward a more patient-centered care approach and patients become more educated on their health conditions, providing patients access to their own medical records or to those who are providing care to them will no doubt be demanded.

Implementation of Electronic Scheduling Systems

Practice

Effective scheduling of appointments using electronic systems is highly developed within the health-care system. In the United States, a majority of clinicians and hospitals use electronic scheduling systems. What is less prevalent is permitting patients and caregivers to access these schedules to make their appointments directly with their providers. A number of the many web-based scheduling systems available offer this service as an option, but relatively few clinicians or health-care systems are allowing patients to make their own bookings. The Geisinger Health System example describes one such system; another is the High Plains Rural Health Network, which provides an Internet-based scheduling service to the Network and involves 20 hospitals. The service allows users such as administrators, doctors, and patients to schedule health-care appointments in real time over the Internet (Versweyveld, 2001).

Research on Electronic Scheduling Systems

No formal research on electronic scheduling systems could be located at the time this chapter was written. However, one might extrapolate research recommendations from the research that has been conducted related to electronic medical records, as some of the same issues and barriers are likely to affect electronic scheduling systems. McDonald (1997) noted that electronic medical records (EMR) were difficult to construct, because existing data sources reside on isolated information technology “islands” with differing structures and coding systems. He suggested that the most important goal for those interested in implementing EMR systems, including scheduling systems, is to adopt a standard system for coding data and communicating over health information networks. In a study of user attitudes toward an EMR system, factors such as professional role and computer experience were found to affect end-user satisfaction with an EMR system at 6 months post-installation (Gamm et al.,1998). Before installation, clinical personnel and nonclinical staff were more likely to expect the EMR to be helpful. Post-installation, nonclinical staff rated the EMR as significantly more useful than physicians and clinical staff perceived it to be. Health-care professionals with lower reported computer experience reported greater computer anxiety related to using the EMR, and most staff experienced a steep learning curve in using the EMR system (Gamm et al.). Research is obviously needed related to the costs and benefits specific to electronic scheduling systems, and more research is needed related to implementation of electronic medical records in general.

Chronic Disease Management and Electronically Delivered Care in the Home

In Practice

Chronic illness is particularly challenging in rural areas for several reasons. First, a statistically higher percentage of the population has chronic diseases in rural areas. Second, services in urban settings supporting the needs of the chronically ill are often not available in many rural communities (Rosenthal & Fox, 2000). Third, there are diseases in both adults and children that previously were fatal, but now because of new medical treatments have become chronic conditions. However, these diseases often require specialty management, and in some cases, such as renal failure, require specialized equipment (Edefonti et al., 2003). Finally, these conditions often require the coordination of care at multiple levels. This can include care from family and/or nurses at home, ambulatory care providers, and hospital personnel in inpatient and outpatient settings. For rural patients, this care is often provided in distant urban communities requiring significant travel. For some of these conditions, travel can constitute a health risk and be logistically difficult, particularly for those requiring ventilator support or other special needs. There are obvious benefits of bringing care to the rural community and the home.

Technology provides several opportunities for those living in rural areas with chronic illness, including monitoring, assisting, and assessing patients, especially for homebound patients. Although most of these solutions have been implemented in urban areas, many of these technologies could be just as effective in rural communities. The applications of these technologies break down into several categories. The first is *Internet-based, self-directed or prescribed education* about the disease. Second are *lay communications and support* through one-to-one e-mail or through support group chat rooms. The third is *e-mail communication with one's own provider.*

And finally, *home telemedicine* facilitates the exchange of data such as cardiac monitoring information, weight and blood sugars, digital imaging of wounds with specialized equipment, and interactive video and live stethoscopy, blood pressure monitoring, and pulse oximetry.

Telemedicine has been used fairly extensively for the care of patients with chronic diseases such as diabetes, asthma, and patients with a chronic wound. Telemonitoring, also known as remote monitoring, integrates a variety of devices including medication organizers and reminders, and devices that measure glucose levels, heart rate, blood pressure, SPO_2, weight, temperature, prothrombin time, and pulmonary function. Further, monitoring systems allow patients and caregivers to respond to questions regarding their current health condition. Responses and data are then sent to a central location where patients can be monitored. Most systems allow for storage of several data points so the patient's progress can be evaluated over time. Store-and-forward technologies are typically used in the field of dermatology and wound management to assess patients at remote locations and can be used in the home-care setting.

Research on In-Home Chronic Disease Management

In 2002, fewer than 200 home health programs were using telemedicine (Field & Grigsby, 2002); however, many of these organizations are now seeing the benefits of several of these home-care technologies. Several groups have reported cost savings related to the provision of telehome care and remote telemonitoring. Telehome care and telemonitoring has been found to save mileage time and prevent hospital admissions and emergency room visits (Chetney, 2002; Dimmick et al., 2003; Johnston et al., 2000; Nesbitt et al., 2006).

Rogers and colleagues investigated the monitoring of mean arterial pressure in a randomized controlled trial of 121 patients and found that the use of telemonitoring was effective in decreasing blood pressure. It also found hypertension to increase when a patient was managed by usual care (Rogers et al., 2001). In a study of CHF patients, after initiating a telehealth program, a 95% decrease in hospital admissions and a 90% decline in emergency room visits was realized (Chetney, 2002). Another study by Dimmick and colleagues realized only a 14% readmission rate for CHF in their telehome care program during its first 6 months and postulated that telehealth intervention for CHF patients could ultimately reduce the national cost of CHF hospitalizations from $8 billion to $4.2 billion a year (Dimmick et al., 2003).

Rural home health agencies may be deterred from pursuing telehome care for reasons related to rural health infrastructure such as limited staffing, lack of experience using technology, inadequate access to necessary technological requirements, and poor reimbursement (Celler et al., 1999; Nesbitt et al., 2006). Most studies in this field included only a small number of patients; larger randomized controlled trials in the field of telehome care could further prove the case for telehome care.

The Use of Telemedicine for Specialty Consultation

Practice

Real-time, *two-way* video-conferencing has been used in health care for almost 40 years, with some interesting work done by several academic institutions and the federal government (primarily the Department of Defense and NASA) during the 1960s and 1970s (Perednia & Allen, 1995). Today, telemedicine exists in all 50 states, with thousands of consultations being performed every month.

Real-time video-based telemedicine is a video-conference between a specialist and a patient (often including a caregiver) in a remote location with or without the referring provider present. This type of consultation allows specialty expertise to be brought to the point-of-care and customized to a particular patient. Telemedicine allows for a collaborative model of care that is difficult to recreate in traditional referral models. This is particularly true when the referring physician participates in an interactive video consultation, presents the patient to the consultant, and works with the consultant to review and implement diagnostic and treatment options. In addition, the video-consultation provides an educational opportunity for the referring physician.

Although a video transmission is possible using a typical analog phone line, depending on the visual needs of the service, most video-conferencing telemedicine makes use of systems capable of near television quality that requires high bandwidth. For example, specialty services that require the visual observation of fine movement (e.g., neurology), facial expression (e.g., developmental pediatrics), or perhaps conversation that emulates the feeling of "real life" (e.g., endocrinology) will utilize a higher end video-conferencing system. Many programs attach scopes to a two-way video-conferencing unit, such as a high-resolution, magnifying camera for observing dermatologic lesions or wounds, video otoscope, or video-nasopharyngoscope. Electronic stethoscopes have also been used for the transition of audio output to pulmonologists and cardiologists. In specialties in which the consultant needs to palpate or perform a procedure, the primary physician at the remote location serves as a surrogate examiner. Laboratory data, ECGs, and imaging studies can be transmitted. This is more than adequate for many conditions in several specialties.

Currently, telehealth programs are branching out into areas that differ from the traditional outpatient clinical consultation model. In the future, there will be more growth on the inpatient side of remote consultations, such as remote inpatient consultations with specialists, or remote emergency consultations that link pediatric intensivists to rural emergency departments when a severely ill or injured child is admitted. Inpatient telepharmacy consultations, which allow a remote pharmacist to review medications being administered during off-hours for hospitals that lack 24-h pharmacist coverage, will likely increase as accreditation requirements become stricter in this area.

New technologies continue to improve the telemedicine experience. Access to high definition and telepresence video-conferencing systems continue to enhance telemedicine capabilities. Broadband capabilities at rural health facilities have become a topic of interest as technology has become more robust. In 2007, the Federal Communications Commission (FCC) allocated over $400 million to develop 69 broadband telecommunication networks dedicated to increasing access to telemedicine and telehealth services in rural areas (United States. Federal Communications Commission, 2007).

Research on Telemedicine for Specialty Consultation

Overall video-based telemedicine has been well received by providers, patients, and families (Nesbitt et al., 2000). The medical literature also suggests that video-based telemedicine has been successful in improving access to care. Multiple studies have shown telemedicine to have benefits in terms of diagnosis and treatment for a wide range of diagnoses for adults, children, and geriatrics (Hersh et al., 2001; Wootton et al., 2000). Clinical guidelines have been developed and promoted by multiple organizations including the American Telemedicine Association, Office for the Advancement of Telehealth, and other specialty societies. It has been shown to be generally acceptable to patients in terms of satisfaction (Nesbitt et al., 2000). Further research has determined its cost-effectiveness (Hilty et al., 2004). Studies show that telemedicine empowers patients, providers, caregivers, and communities. For example, patients have reduced travel time, reduced absence from work, reduced waiting time, and experienced more choice and control (Hilty et al., 2002). A recent study also demonstrated that rural residents have higher opinions about the quality of local providers when those providers have telemedicine capable offices (Nesbitt et al., 2005).

Challenges in the Provision of E-Health Services to the Rural Home and Community: Policy and Training Issues

A significant digital divide exists nationally between rural regions, where greater proportions of low-income families live, and urban communities. It is exacerbated by higher rural infrastructure costs and lower average wages, which generally limit new information technologies. In larger urban centers, population density and larger markets reduce the costs of infrastructure development. When appropriate infrastructure is installed, connection speeds are generally slower and costs considerably higher, although wireless technology may possibly change this situation. These trends are alarming considering that the majority of the world's population lives in rural areas.

Telecenters and community portals may be a solution for the divide, particularly for lower income populations and for those who need to access services that are not available in their communities (Dart & Yellowlees, 2008). Telecenters could access information technologies. Community portals could allow for improved context specificity of health information delivery as well as serve as a gateway to validated, reliable sources of health information. Skilled "informationists" could mediate the development and function of these rural community-based centers and portals to target appropriate health information and thereby overcome some of the consequences of the rural digital divide.

Most failures of technology are attributable to human factors (Perednia & Allen, 1995). The integration of technology in the health-care environment is often a challenge, particularly when the technology is viewed as interfering with the traditional face-to-face relationship between a clinician and patient. In addition, clinicians and patients may resist technology due to lack of familiarity with it. For the e-health-enabled model of rural health to be effective, individuals and organizations must be comfortable with the technology and understand its benefits. In addition, while with the traditional model of face-to-face care the clinician was in control, the new model of care requires a collaborative approach to care delivery, necessitating shared control and decision making, and added organizational complexity.

It is critical to introduce these technologies in a nonthreatening manner, particularly for more advanced technologies such as video consultation. It is important that technology be "user friendly" and that the users be involved in the selection process. An assessment of needs, preferences, and concerns *in advance* of purchase and implementation is important (Bashshur et al., 1994). Equipment must be convenient to use and reliable. It must enable the user to do a particular task better and provide a better service to the patient. A significant amount of preplanning, analysis, and education must precede the introduction of technology. This training process should move from concept to application at a rate that is comfortable to the participants and include continuous training to maintain proficiency. For rural clinicians, it is important to emphasize throughout the process that the technology provides tools to enable the clinician to better meet the care needs of the patients and keep them in their communities.

Conclusion

With all of the scientific advancements that are being made in health care, it is important to realize that all of this science is only as valuable as the system's ability to get the science to those who need it: patients and caregivers. If we discover the cure for cancer in the laboratory but only half the people with cancer have access to it, have we not discovered only half of the cure for cancer? The culture of health care must change to this way of thinking if we are to have the will to make the necessary changes to resolve the geographic disparities that exist in health care today. Within the United States, several legislative bills have been proposed to provide better reimbursement for many of these services and to encourage the use of technology; however, there is still a long way to go. Government policies that offer incentives to providers to make the steps toward using technology are recommended.

Health care is in the process of a major evolution. Technology will play a major role in this evolution, but not without its challenges, particularly in rural communities (Institute of Medicine, 2004). The solutions to these challenges are multiple and will continuously shift and alter over time. It is crucial that adopting technology, however, is not seen purely as a technological issue. It must be defined as a human and health-care process issue where the needs and opinions of patients and caregivers are central. As health-care changes become consumer- and caregiver-driven, patient-focused, evidence-based, and protocol-supported, with increasing emphasis on safety and quality, it is critical that policy makers and the public realize that geographic equity is one of the dimensions of quality as outlined by the Institute of Medicine. Technology is not an answer in itself, but it has the potential to assist in the improved distribution of information and expertise as well as play a major role in creating healthier rural communities.

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Part IV
Assistance Strategies

Chapter 10
Education, Training, and Support for Rural Caregivers

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Enabling individuals to live in the community despite health-care needs is an important and growing public policy concern. Providing services (preventive, support, remedial) for family caregivers is critical to the maintenance of care recipients' health and well-being. Caregivers need a variety of knowledge and skills in order to be effective and, given the relative lack of services in rural areas, rural caregivers may have an even greater need for skills. Unfortunately, most of the interventions with caregivers have been tested on primarily urban samples. This chapter is an overview of the various education, training, and support needs that should be addressed in rural caregiver interventions and support programs as well as a consideration of the practice, research, training, and advocacy needs of rural caregivers.

What Caregivers Need

Strength of an intervention, and thus the likelihood of a successful outcome, can be defined in terms of the amount and intensity of the treatment, adequacy of the theoretical rationale for the treatment, and the clarity of the links between the intervention and the outcome (Bourgeois et al., 1996). Caregiver interventions should be built on a foundation of theoretically and empirically established relationships among psychological constructs relevant to caregiving, such as cognitions, stress, and coping. Based on existing research, interventions with caregivers have the potential to be most effective if they are designed to be a relatively comprehensive "attack" on the caregiving situation, targeting various important aspects of the caregiver burden-outcome process (Chwalisz, 1996; Schulz, 2000). Effective interventions can be identified related to the domains of knowledge, skills, affect, and support.

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Knowledge

Psychoeducational programs are often focused on skill development over time-limited sessions with specific goals. The primary focus of such programs is on the personal needs of the caregiver (e.g., anger management) or other practical aspects of caregiving such as lifting skills or behavior management. Various controlled trials and case controlled trials of caregiving training programs, particularly when the training was targeted to specific aspects of the care recipient's condition (e.g., managing agitation in dementia), have revealed such training to be effective (Teri, 1999; Thompson and Gallagher-Thompson, 1996). However, Kennet et al., (2000) observed that treatment effects were often not found for knowledge-based interventions, and they suggested that an interventions targeted to caregiver knowledge alone might have a limited impact, especially on more global outcomes such as caregiver burden.

Caregivers may be trained regarding the *caregiving process/role*, based on the assumption that caregiving is a *career* with "dynamic and evolving demands, activities, and dispositions" (Pearlin, 1992, p. 647; Skaff et al., 1996). Understanding the natural progression of caregiving can facilitate caregiver coping and help professionals identify a caregiver's needs by his or her stage in the process. For example, if a caregiver is in the initial stages of the role (e.g., care recipient has just been released from the hospital), more of the knowledge intervention involves general planning and resource acquisition. In contrast, caregivers in the later stages of the caregiving process might be presented with knowledge that focuses on things such as protecting against role engulfment (Skaff & Pearlin, 1992), maintaining a healthy lifestyle (e.g., Janevic & Connell, 2001), or managing behavioral problems (e.g., Teri, 1999). Czaja et al., (2000) recommended that interventions with caregivers should be continued beyond care recipient institutionalization and death, because important aspects of the caregiving role continue beyond institutionalization. Caregivers in these later phases of the caregiving process would receive knowledge such as dealing with nursing homes, hospitals, and hospice programs; and be presented material on stress, grief, and loss (including anticipatory grief) among caregivers (e.g., Meuser & Marwit, 2001; Gaugler et al., 2000).

Caregivers also need *knowledge of the care recipient's condition and treatment options.* Given the relatively low incidence of various physical and mental illnesses, associated with the lower population density of rural areas, it is unlikely that professionals will be able to specialize in terms of a particular care recipient health condition. It is obviously impossible to know everything there is to know about every care recipient condition that one might encounter. Thus, professionals should focus on developing excellent information-seeking skills and building caregivers' information-seeking skills. Caregivers should be taught about the types of information that are important to know (e.g., course/prognosis, related sequelae, effects of comorbidity), general information-seeking strategies, and potential sources of such information (e.g., professionals, books, Internet, area agencies on aging).

Information about *available resources and services* is also critical for successful caregiving. Helping caregivers to access services is particularly challenging in rural areas where resources are scarce, and coordination of services and resources is less likely. Integration of services is important, as caregivers may have a hard time navigating separate specific services which may be quite spread out in rural areas (O'Reilly & Strong, 1997). Coalitions of agency professionals can assist in service coordination and referral.

Another type of knowledge needed by caregivers is related to *important issues and/or procedures*. Important issues/procedures that are almost universally experienced by caregivers are legal issues (e.g., power of attorney, health-care proxy), dealing with government agencies (e.g., Medicare, IRS), and financial issues (e.g., spend down to Medicaid eligibility for nursing home placement) (Thompson & Gallagher-Thompson, 1996). Little or no research has been directed toward examining this type of knowledge need, whereas these issues come up for nearly all of the caregivers we work with, and legal questions are among the most frequently asked in our rural caregiver helpline program (Chwalisz & Clancy Dollinger, 2002).

Skills

Caregivers need a variety of skills, both specific and general. First, caregivers may require specific *care-related skills* such as lifting, dealing with medical equipment, or daily medical maintenance (e.g., changing dressings, testing blood sugar). Behavior management skills (e.g., managing wandering or aggressiveness in dementia) may also be needed (Carnevale et al., 2002), although behavior management skills training alone may not be sufficient to impact caregiver distress (Burns et al., 2003).

A variety of *communication skills* are required by caregivers, depending on their unique backgrounds and needs. For example, assertiveness training might be used with caregivers who are having difficulty getting information from professionals or assistance from other family members. Done and Thomas (2001) found that caregivers could be trained to structure questions for more successful communication with care recipients with Alzheimer's disease. Greater communication competence among caregivers has been related to lower levels of stress, less depression, and greater social support (Query & Kreps, 1996; Query & Wright, 2003).

Perhaps the most far-reaching and well-researched of the general (i.e., generalizable) skills are *social problem-solving skills*. The ability of the caregiver to analyze his or her situation is critical to effective caregiver functioning (Schulz et al., 2000). FOCUS social problem-solving skills training (Kurylo et al., 2001), involving a systematic consideration of problem-solving facts, optimism, creativity, understanding, and solutions, has been used to train caregivers to more effectively examine and develop solutions to their problems. Problem-solving self-efficacy, ability to gather relevant information, creativity in generating possible solutions, effective choice among solutions, and the ability to evaluate the results of one's efforts are important skills for caregivers. Social problem-solving abilities appear to be an important predictor of physical and emotional health among urban and rural caregivers of persons with a variety of concerns (e.g., Grant et al., 2001; Houts et al., 1996). There is even some evidence that caregiver problem-solving affects care recipient outcomes such as acceptance of disability and health complications over time (Elliott et al., 1999).

Caregivers may also need assistance in developing effective *coping skills*. Coping skills are important in any stressful situation, but they can be particularly important with the chronic stress of caregiving. A greater emphasis on problem-focused coping (i.e., efforts to change aspects of the situation), as opposed to emotion-focused coping (e.g., distraction, denial), is associated with better caregiver outcomes (Chwalisz, 1996). Research on coping skills interventions suggests that programs targeted to improve specific coping skills can have a significant impact on caregivers' distress (Gallagher-Thompson et al., 2000).

Affect

Caregivers experience a wide variety of negative emotions (e.g., guilt, frustration, anger, sadness, grief). Intervention programs should include strategies directed toward managing negative emotions, as these negative emotions can directly impact caregiver's psychological difficulties (e.g., depression and anxiety). Helping caregivers manage negative emotions should also decrease the use/need of emotion-focused coping strategies (e.g., distraction, denial, self-isolation) that have been associated with higher levels of perceived stress (Chwalisz, 1992). Some researchers and theorists have begun to focus on increasing the positive aspects of caregiving such as improved self-efficacy and self-respect (Davis, 1992) and finding meaning in the role (Butcher et al., 2001). Other general efforts to increase positive emotions (e.g., engaging in enjoyable activities, exercise) are also helpful.

Cognitive-behavioral therapy (CBT) appears to be particularly useful in helping caregivers manage negative affect. Interventions based on CBT have been widely implemented with demonstrated effectiveness (e.g., Thompson and Gallagher-Thompson, 1996). Cognitive behavior therapy may be used to help caregivers combat irrational beliefs that contribute to stress in the role. Irrational beliefs have been most often related to negative emotions among caregivers in our caregiver support group research (Chwalisz et al., 2000). In addition, caregivers have exhibited a variety of irrational beliefs surrounding issues of self-care (e.g., not believing one has time or deserves to make time for self-care, prohibitions to setting limits with the care recipient, conflicts about being assertive with health professionals or family members).

Specific techniques related to stress management (e.g., relaxation training), and anger management might also be included in affect-oriented interventions with caregivers. Various applied relaxation techniques such as breathing exercises and progressive muscle relaxation (Davis et al., 2000) can be helpful for caregivers experiencing the physiological aspects of stress. These approaches have been found to activate the parasympathetic nervous system (Mashin & Mashina, 2000) and appear to be effective for individuals with a variety of anxiety and stress-related problems (Carlson & Hoyle, 1993), although relatively little research has been directed toward testing these techniques specifically with caregivers (c.f. Olshevski et al., 1999).

Social Support

Contact with others is an important factor in caregiver well-being (e.g., Chwalisz, 1996; Skaff & Pearlin, 1992). Caregivers, in general, have been found to be socially isolated, but isolation is an even greater concern for rural caregivers (Buckwalter, 1996). Social-support-oriented interventions with caregivers tend to involve support groups, with the assumption that putting caregivers together in a group will enhance support. Difficulties related to transportation to support group meetings and finding alternative care for the care recipient are barriers to support group attendance, particularly for rural caregivers who may have to travel longer distances to access a group. The outcomes measured in support group research have tended to be global physical or mental health outcomes. Such studies have yielded small effect sizes (Knight et al., 1993). A few interventions directed at impacting the caregiver's actual level of support are promising (e.g., Cohen et al., 1998; Hansell et al., 1998).

For some caregivers, especially rural caregivers who are isolated, development of skills related to *increasing the size and range of the support network* may be important. This may involve interventions geared toward identifying potential supporters, strategies to find/engage supporters, and social skills training (Vaux, 1988). In some cases, caregivers may have inaccurate perceptions of available support (e.g., not recognizing supporters who already exist), and professionals may help caregivers develop more realistic perceptions/expectations. Support groups are particularly helpful for rural caregivers who can become very isolated (Sullivan et al., 1993), although problems with transportation and care for the loved one while attending can prohibit support group attendance.

Other caregivers may need help in *maintaining existing support*. Logsdon and Robinson (2000) described an example of a typical caregiver who over time has been so busy with caregiving duties that she failed to attend to maintaining her support network and later finds herself without sufficient people from whom to seek help. Caregivers often report that they lose touch with their support network, or supporters drift away due to discomfort surrounding the caregiving situation (e.g., Chwalisz & Stark-Wroblewski, 1996). Caregivers need to do various things to maintain their networks, as social relationships are generally reciprocal in nature (Vaux, 1988), and caregivers may need to be reminded of or taught network maintenance skills.

Some caregivers may have adequate support systems yet still have support deficits, and they need assistance in *getting more help from the network.* Asking for help is particularly challenging for caregivers, who are in the role because they are generally the highest functioning individuals around (Chwalisz et al., 2000). This aspect of social support intervention involves training caregivers in asking for help or assertiveness (Chwalisz & Clancy Dollinger, 2002; Logsdon & Robinson, 2000).

Summary: What Caregivers Need

Caregiving is a complex social and psychological phenomenon, and caregivers may need assistance in a variety of areas in order to function effectively in the role. Empirical support has been accumulating for caregiver interventions that include the domains of knowledge, skills, affect, and support. However, much of the evidence related to components of caregiver interventions is based on convenience samples of urban caregivers, and the effects of rural culture as well as other cultural variables (e.g., race/ethnicity, age, gender, sexual orientation) have not been adequately considered (National Institute of Nursing Research [NINR], 2001). Furthermore, the relative importance of the different areas of intervention has not been elucidated.

Practice Issues: Delivering Caregiver Interventions

Researchers and practitioners who work with caregivers have been amassing information about what caregivers need. However, professionals, policy makers, and the health-care system must also attend to how such interventions may best be offered and delivered to rural caregivers. This section is a consideration of the literature on the nature of caregiver interventions.

Several leading researchers of informal caregiving have conducted reviews of the vast literature on caregiver interventions (e.g., NINR, 2001; Thompson and Gallagher-Thompson, 1996; Schulz, 2000). As a comprehensive review of the caregiver intervention literature is beyond the scope of this chapter, the findings of previous reviews will be used here. Various theoretical and empirical models capture the complexity of the caregiving process (Chwalisz, 1996; Lawrence et al., 1998; Pearlin et al., 1990; Yates et al., 1999). Numerous caregiver interventions have been developed and tested with informal caregivers, yet they vary in effectiveness and often have limitations (Schulz, 2000; Toseland and McCallion, 1997; Thompson & Gallagher-Thompson, 1996). In spite of widespread client satisfaction, effect sizes for caregiver interventions have ranged from moderate to, and in many cases, small effects.

Individual Versus Group Intervention

Reviews of caregiver interventions indicate that individual services are more effective than group interventions (Cooke et al., 2001; Knight et al., 1993). However, the lack of focus on strategies to improve life quality and problem solving is often cited as a limitation of caregiver support groups (Gallagher-Thompson et al., 1998). Thus, it is not clear whether the small effect sizes associated with group interventions are due to the group modality or simply that poorly designed interventions are more likely to be presented in a group format.

Also to be factored into comparisons of group versus individual interventions, is the fact that group interventions are more likely peer-led. Toseland et al. (1990) identified distinct processes operating in peer-led versus professionally led caregiver groups. Whereas no statistically significant difference in group effectiveness was found in the Toseland group's study, peer-led groups were more effective in terms of social processes (e.g., amount of social interaction, amount of discussion of community resources, extent to which leader served as role model). In addition, professionally led groups were more effective in terms of therapeutic processes (e.g., discussing specific problems, gaining insight and awareness about the nature of problematic situations, development of effective coping skills). Caregivers also tend to prefer professional services to those provided by peers (Bourgeois et al., 1996).

More research is needed in terms of peer versus professional interventions with caregivers. Peer-based interventions might be especially relevant in rural areas, where there is often a shortage of qualified professionals. Research should be directed toward identifying and elucidating the positive aspects of peer-based caregiver services, and ways to improve the quality of peer-based interventions (e.g., training, supervision) should be identified.

In-Person Versus Telehealth Interventions

Telehealth interventions have been posited as a means of bridging the gap between health-care services in rural and urban areas. Stamm (1998) suggested that "telehealth can transcend troublesome boundaries like economic status, culture, climate, geography, and even warfare" (p. 536). Positive aspects of telehealth services include reduced long-term costs, increased accessibility for those who are not willing or able to travel, privacy, and increased comfort with being able to receive services in one's own home (Wright et al., 1999).

Telecommunications has supported health care for many, and no difference has been found on key therapeutic variables (e.g., therapeutic alliance, client satisfaction) between in-person, audio-only, and audio-video modalities (Day & Schneider, 2000). In one telehealth program, for example, a weekly telephone intervention provided support and assistance to family caregivers of dementia patients and also served to provide information on area social services. Caregivers experienced less distress, hostility and feelings of burden after the intervention (Strawn et al., 1998). An intervention designed for dementia caregivers with a primary focus on anger management has also successfully used telephone calls as a means to reach caregivers (Steffen, 2000). In a more sophisticated design, telephone training appeared to be as effective as in-home training in reducing distress and burden among caregivers of individuals with Alzheimer's disease, but the telehealth training took longer to reduce burden and was associated with a higher rate of caregiver attrition (Davis et al., 2004). Telehealth interventions with rural caregivers have also incorporated more sophisticated technologies. For example, Buckwalter et al., (2002) described an in-home audio/video system, in which caregivers are connected to a base station via a standard telephone line.

There is good initial support for the use of telehealth approaches with rural caregivers. Although some very innovative and sophisticated technologies have been used to get caregiver support into the home, it appears that the technology need not be terribly complicated to be effective. More research is needed in the area of telehealth intervention with rural caregivers – particularly comparing telehealth services with traditional services, comparing different technologies, and cost–benefit analyses of such services.

Multicomponent Versus Targeted Interventions

There is theoretical and empirical support for the hypothesis that multicomponent interventions are superior to more targeted interventions (see Schulz, 2000; Thompson & Gallagher-Thompson, 1996), and interventions with greater frequency and intensity are likely to be more effective (Kennet et al., 2000). Support is available for various types of interventions, with content from the previously described domains relevant to caregiving (Schulz et al., 2000; Kennet et al., 2000). Targeted multicomponent interventions have been shown to yield sustained effects on caregiver well-being. For example, Mittelman et al. (2004) demonstrated that a counseling and support-based intervention was superior to treatment as usual in decreasing depression in spouse caregivers of patients with Alzheimer's disease, and the effects were sustained for more than 3 years after the initial intervention. Furthermore, the full benefits of the treatment were realized only after all treatment components had been received.

More information is needed to answer questions about multicomponent versus targeted interventions such as on dose–effect relationships (Kopta, 2003). How much assistance and how many components are necessary to see benefits for caregivers? Are there certain combinations of caregiver support components that are more effective than others?

Standardized Versus Tailored Interventions

Bourgeois et al. (1996) recommended attending to specific caregiver characteristics and tailoring interventions to the individual. Whereas multicomponent interventions appear to be superior to specific interventions, the nature and appropriateness of the specific interventions included in those comparisons were not investigated. One important research question that has yet to be answered is whether a specific intervention, tailored to unique caregiver characteristics, is more effective than a standardized multicomponent caregiver intervention. Obviously, a "shot gun" approach has a greater probability of tapping a given caregiver's needs when offered to a group of caregivers about whom interventionists have little information. However, caregiver intervention might be more efficient if particular intervention components could be matched to assessed client dimensions. The question of tailored versus standardized interventions needs to be examined, and if tailored interventions have potential, efforts need to be directed toward assessing critical caregiver dimensions and identifying the associated intervention techniques.

Preventive Versus Support/Remedial Services

As previously noted, caregivers may benefit from different kinds of assistance at different stages in the caregiving process. The majority of caregiver interventions to date have fallen into two main categories: (a) interventions offered in medical or rehabilitation settings, focused on educating and preparing caregivers who are new to the role; and (b) support-based interventions for caregivers whose activities are ongoing. Very little is known about services that are more remedial in nature, directed toward the overburdened caregiver who is in danger of breaking down from the role. In fact, overburdened caregivers were identified, in a state-of-the-science workgroup meeting, as a caregiving population in need to increased attention (NINR, 2001). Many people do not access services until they have exhausted their available resources (e.g., Fish, 1990).

More research needs to be directed toward examining the best ways to deliver different types of services to caregivers at different points in their caregiving career. For example, we have found that overburdened caregivers are accessing our telehealth program at a much greater rate than caregivers who are earlier in the process (Clancy Dollinger et al., 2004). Thus, telehealth services may be a better way of providing remedial services to overburdened caregivers, whereas medical settings may be more appropriate for preventive services, when caregivers are a "captive audience" so to speak.

Research on Interventions with Caregivers

A great deal of research has been conducted on how best to provide education, training, and support to caregivers. Several conclusions and recommendations are available, based on various reviews of the intervention research literature, to guide future caregiver programs and research. Caregiver interventions (and components thereof) have often lacked a theoretical basis (Biegel & Schulz, 1999; Bourgeois et al., 1996). Caregiver intervention research has often been conducted with convenience samples of White urban caregivers. Population-based data on informal caregiving are limited, and various subpopulations of caregivers have been targeted for more research such as rural, ethnic minority, intergenerational, and overwhelmed caregivers (NINR, 2001).

Outcome measures used in caregiver intervention research have often not been sensitive to change, yielding small or no post-intervention effects (Cooke et al., 2001). Several reviewers have identified a need to collect baseline data (e.g., Cooke et al., 2001), and larger effect sizes have been predicted for outcome measures more closely linked to the targets of the intervention (Biegel & Schulz, 1999; Thompson & Gallagher-Thompson, 1996; Schulz, 2000) and measurements taken at longer post-intervention intervals (Cooke et al., 2001). More specific efforts to ensure the fidelity of treatment implementation have also been suggested (Biegel & Schulz 1999; Burgio et al., 2001), and treatment researchers would do well to incorporate more sophisticated approaches involving recording/observing and rating sessions for treatment fidelity. Methodological, measurement, and design issues such as these need to be addressed in future caregiver intervention research, before we can trust in and generalize conclusions drawn from such research. Furthermore, more research must be conducted specifically with rural caregivers, and the unique aspects of interventions with rural caregivers as well as methodological and design issues unique to rural caregiving research must be elucidated.

Providing Services to Caregivers: Policy and Advocacy

Policy related to family caregiving has not advanced at the same rate as knowledge regarding other aspects of caregiving and assisting caregivers, and this trend is even more salient with regard to rural caregiving. Kane and Penrod (1995), in the introduction to their edited book on policy issues in family caregiving, noted two reasons to pursue the development of policy related to family caregiving. First, policy has the power to shape people's lives toward positive images of how caregivers and care recipients should interact. Second, policies may be developed to correct what appear to be problems in family and community life. For example, if the costs of long-term care are too great, then policy may be developed to encourage family members to provide more care such as tax credits for caregiving. If it is determined that family members are not providing adequate care, policy might support the development of ways to improve caregivers' performance. If caregiving is deemed to create excessive distress or burden among family members, then policies should be directed toward addressing that problem. In 2000, Congress reauthorized the 1965 Older Americans Act and created the National Family Caregiver Support Program (NFCSP) to provide services to caregivers such as information, respite care, counseling, training, and support groups. Although the initial funding for the NFCSP was just about $5 per caregiver, appropriations have been increasing (National Council on Aging, 2007). As this program is administered on the state and local levels, innovative programs may emerge to assist caregivers, and rural caregivers need attention as such programs are developed.

The biggest challenge related to education, training, and support for rural caregivers is encouraging/helping caregivers gain access to services. A number of factors have been identified such as geographic distance, lack of knowledge, stigma associated with accessing services, suspicion, and services that are not responsive to rural culture (e.g., Buckwalter & Davis, 2002; Ham et al., 2003; Sullivan et al., 1993). Rural caregivers are likely to rely on informal care networks and are reluctant to engage in preventive services and support groups. Better coordination and networking of services is needed in rural areas (O'Reilly & Strong, 1997). Models, projects, and evaluations need to be specifically targeted to rural populations and designed to address the unique challenges posed by rural life (Lishner et al., 1996).

Well before caregivers consider accessing services, however, they must first recognize a need for services. Greene and Coleman (1995) observed that to date services have not been utilized to their full extent, and they suggested that the provider community may be ahead of family caregivers in terms of recognizing caregiving as a social fact. Innovative services and service-delivery mechanisms need to be developed to address issues of access, or perhaps more importantly caregivers' *accessing* behavior. Caregiving is a role that is so common and expected that many individuals consider it a normal and typical activity and part of an expected developmental stage of life (Greene & Coleman, 1995) – not one for which services need to be sought. Many caregivers do not even view themselves as in a caregiving role, unless a particular problem is diagnosed in a care recipient (O'Reilly & Strong, 1997; Waite and Knapman 1993). Cultural factors (e.g., race/ethnicity, socioeconomic status, age, sexual orientation, disability status) also interact with perceptions of caregiving stress and the need for services as well as caregivers' willingness to seek help (e.g., AARP, 2001; McFarland & Sanders, 1999; Wykle & Segall, 1991). There is a serious need for research directed toward understanding caregivers' reluctance to utilize services and developing means of combating psychological barriers to service utilization.

Another critical policy/advocacy issue related to assisting rural caregivers is funding. The most direct approach to helping family caregivers is through policies that provide financial assistance or compensation for family members who provide care (Linsk et al., 1995). Compensating family caregivers may be particularly relevant to rural caregivers, given the relative scarcity of professional caregivers in rural areas. Cash, allowances, vouchers, and tax incentives (e.g., exemptions, credits, deductions) are some of the ways in which caregivers may be compensated for their efforts. Linsk and others reviewed various caregiver compensation programs and made a number of policy recommendations. They suggested that caregiver family payments could be based on care needed or provided, and benefits and services (e.g., cash transfers to consumers, caregiver fringe benefits, complementary consumer services) should be combined in such ways as to encourage potential caregivers to stay in the paid labor force. Current federal and state matching programs might be utilized by states in setting up caregiver compensation programs, and Linsk and others (1995) offered a number of suggestions regarding how to administer such programs and ensure quality. Currently, three states (Arkansas, Florida, New Jersey) have been included in Medicaid's Cash and Counseling demonstration project, in which Medicaid beneficiaries are provided with an allowance to arrange for their own support services and counseling to assist beneficiaries in administering their allowances. In Arkansas, caregivers whose care recipients were enrolled in

Cash and Counseling and engaged self-directed services experienced less physical, emotional, and financial strain than caregivers of individuals who received services through agencies (Foster et al., 2005). Informal caregivers in the Cash and Counseling group who became paid caregivers had significantly better outcomes than control group caregivers, but informal caregivers of Cash and Counseling care recipients who remained unpaid had outcomes very similar to the paid caregivers. Foster and colleagues suggested that unpaid caregivers may have otherwise had their loads reduced through the Cash and Counseling self-directed service options. Clearly much more attention needs to be directed toward the funding/economic issues of caregiving, but consumer-driven options appear to be particularly promising.

Conclusions

Whereas much is known about potential domains in which rural caregivers may need and benefit from education, training, and support, there are many more questions to answer. Particularly, professionals and policy makers need to know much more about specific experiences of caregiving in rural America and the important variables that determine healthy and successful caregiving. What aspects of rural culture protect caregivers and improve caregiving; and what aspects of rural culture impede effective caregiving and lead to poor outcomes? Attention also needs to be directed to the needs/experiences of specific subpopulations of caregivers (e.g., ethnic minority caregivers, overburdened caregivers), and factors must be identified that can help providers identify particular types of service needs (e.g., testing questions of tailored versus standardized intervention). Perhaps most importantly, efforts need to be directed toward identifying and removing social, psychological, financial, and political barriers to accessing caregiver services. Education, training, and support can only benefit caregivers – as well as the health-care system and society – if, and only if, caregivers make use of those services.

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Chapter 11

Strategies to Support Rural Caregivers: Practice, Education and Training, Research, Policy, and Advocacy

Carolyn S. Wilken and Brianne McCarthy Stanback

Rural caregivers need support in areas that are similar to and yet very different from their urban counterparts. Regardless of geographic location, caregivers report needs for assistance with physical care of their care receiver, dealing with medical professionals; medication and nutrition issues; managing formal caregivers; financial, legal, and insurance concerns; appropriate and affordable housing; transportation; psychosocial issues of both the caregiver and the care receiver, and family relationships (Bédard et al., 2004; Glasgow, 2000; NRHA, 2004). Caregiving situations in rural communities mirror those in urban settings and include providing care for aging persons as well as children or adults with intellectual or developmental disabilities, or acute and chronic medical conditions. Whereas the types of support caregivers require are consistent across geographic settings, there are significant urban/rural differences in the burdens of providing care, particularly with regard to the availability of formal supports, the levels of reliance on informal support, and the availability of health-care services. Specifically, rural caregivers have access to fewer formal services and rely more heavily on informal systems of support (Bédard et al., 2004; Blieszner et al., 2001; Mier, 2007; Reschke & Walker, 2006).

When developing programs that provide support for rural caregivers, it is imperative to also recognize that embedded within rural communities are ethnic minority families whose caregiving needs are different from, as well as greater than, other rural caregivers as well as their urban counterparts (Coogle, 2002; Eaves, 2002; Kosberg et al., 2007). Not only are minority caregivers underserved (Valle, 1998; Wykle & Ford, 1999), they are often unacknowledged. Programs that support minority caregivers living in rural communities require even more specialized strategies, as

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they are unlikely to seek information and services (see Greer, 2011). Strategies to support rural, minority caregivers must support the basic infrastructure of the families (Wood & Parkham, 1990).

Practice

Current Status

Current practices for providing support for rural caregivers have met with mixed success. Strategies that have proven less successful in meeting the needs of rural caregivers most often fail to account for (or even recognize) the uniqueness of rural culture and communities, taking a one-size-fits-all approach. Developers of such programs presume that their program will meet the needs of all audiences (Falicreek, 2003). For example, a program for caregivers may strongly recommend the use of formal services (i.e., counseling, respite care, bathing services, meal delivery services) that are plentiful in urban settings, but nonexistent in rural communities.

The literature and anecdotal evidence suggest strategies for program development and delivery that will increase the likelihood of program success in rural settings. For example, programs developed and implemented locally have proven to be most successful (Falicreek, 2003; Tremethick et al., 2004). Such programs take into account local needs and customs, available services such as professional and paraprofessional providers (Bliezner et al., 2001), facilities, and transportation (Bédard et al., 2004). Successful programs often have a local champion for the program – a well-recognized person who endorses the program (Wilken & McGhee, 1994). Common practices used by these successful programs include a number of critical components (National Alliance for Caregiving, 2008).

Needs assessments. Due to privacy issues related to sparse populations, demographic data (i.e., census data) often fail to provide the level of information needed to identify actual numbers of caregivers in rural communities. It is, therefore, necessary to conduct local needs assessments. This can be accomplished through a variety of methods, including focus groups, individual interviews, and key informant interviews (Yin, 2003). Caregiving needs can be identified through interviews with key informants, such as the public health nurse, local health-care providers, members of the clergy, representatives of local senior centers, school personnel, Area Agencies on Aging staff, the Association for Retarded Citizens (ARC) workers, and individuals known to be or to have been caregivers (Gilmore & Campbell, 2005). For example, North Dakota State University and the University of North Dakota (NDSU & UND, 2002) conducted an assessment of state residents' needs for a variety of formal services associated with long-term caregiving via telephone interviews with a sample of older North Dakota residents using random digit dialing. Through this assessment, the researchers found that the lack of formal caregiving and health-care services was compounded by accessibility issues related to transportation.

Collaboration. Successful programs, particularly in rural communities, must rely on cooperation between local agencies and service providers in an effort to maximize resources and avoid unnecessary duplication. Collaboration may involve establishing a local coalition on caregiving, which might include representatives from the medical community, public health/home health, the clergy, family caregivers, care receivers, representatives from associations or organizations related to specific caregiving issues (i.e., Alzheimer's Association, ARC, Heart Association), and local businesses (Dodd, 2004). The coalition is in the best position to identify needs and resources as well as understand the culture of the community. The coalition can jointly sponsor programs such as combining a program on a caregiving issue with older adults, or weaving caregiving information into a nutrition education program at the local nutrition site. Successful coalitions use specific strategies for the assignment and acceptance of roles and responsibilities by coalition members (Wilken et al., 1999).

Use local resources. Although it is sometimes necessary to "bring an expert to town" to address specific issues, successful programs make use of local experts with whom the audience is more familiar and who will remain available to provide support over time. Members of the coalition have contacts with experts – local and from out-of-town – who can be called upon to conduct presentations or offer consultation. The Elderberry Institute's *Living at Home/Block Nurse Program* is an example of how local volunteer and professional resources can relieve caregiver burden and reduce instances of unnecessary or premature nursing home placement. The goal of the program is to bring together the resources of a community in response to people needing care (Elderberry Institute, 2004). This program, which originated in Minnesota and has 35 in-state locations (as of 6/24/07), has been successful in other rural states, such as North Dakota and Texas.

Program champions. Programs that have the support of a local celebrity or trusted public figure garner the attention and often the trust of potential participants. Likewise, former and present caregivers who can share personal experiences enhance program marketing. This strategy is particularly effective in rural communities where people know one another (Wilken & McGhee, 1994).

Transportation. Distance between communities, frequently impassable roads, and bad weather can make traveling in rural communities particularly difficult. Public transportation in rural communities is usually nonexistent. Successful programs must be located in an accessible area. Various research centers and agencies, such as the University of Wyoming, University of North Dakota, and the Idaho Department of Health, have begun "mapping" to develop more efficient and specialized systems of transportation and to devise a strategy for identifying accessible sites to establish support service agencies, professional offices, and educational locations (Center for Rural Health Research and Education n.d.; Weng et al., 2005).

Stay at home. While many rural caregivers are able to "come to town" to participate in a caregiving program, doing so may mean leaving the care recipient alone with no one nearby to provide assistance if needed. Therefore, effective support services for rural caregivers are often delivered to the caregiver's home. Telephone checking services, educational materials delivered by mail or via the Internet, home health care, and home-delivered meals are some examples of delivery methods that respond to the needs of rural caregivers (Illinois Department on Aging, 2004; Korsching et al., 2003; McBride, 2008).

Cultural competence. Although rural life is often seen as idyllic, there are aspects of rural culture that impact the successful delivery of programs for caregivers. Rural Americans are known for their self-determination (independence), self-reliance, conservatism, family orientation, distrust of outsiders, and individualism (Blieszner et al., 2001; Bull, 1998). Programs are most appreciated when developers build on this psychological basis by providing caregivers with the support and education or the training they need to remain independent (Falicreek, 2003; Wilken et al., 2002). In the rural caregiving arena, the norm of self-reliance translates to reliance on family rather than professionals. The desire for privacy is a norm of rural culture that can offer special challenges for program delivery in rural communities, particularly when delivering programs that deal with sensitive issues (i.e., family, financial, or health-care issues), or in formats where it would be common to expect confidentiality, such as support groups (Healy, 2003). Service providers are faced with a myriad of ethical concerns, such as a lack of privacy in rural communities and the multiple roles played by formal caregivers (i.e., friend, neighbor, and social worker) when dealing with rural audiences (Healy, 2003). Strategies that incorporate respect for privacy, support independence, recognize the multiple roles played by service providers, and utilize family members and local institutions have a greater chance for success in rural communities.

Future Directions

Given the aging demographics of rural America, the need for caregiving in rural areas is expected to increase dramatically (U.S. Department of Health and Human Services [HHS], 2003a). Future practice considerations include: (a) changing demographics, specifically the relocation of extended family away from the rural community (Glasgow, 2000) as well as the negative replacement factor of professionals in rural communities (HHS, 2003a, b); (b) the importance of fit between caregiver support programs and local needs, resources, and culture (Blieszner et al., 2001; Falicreek, 2003); and (c) the identification of new support models that utilize technology in practical and acceptable ways (Korsching et al., 2003).

Aging of the caregiving population. Programs to support rural caregivers must accommodate the increasing age of the primary caregiver and the ever-shrinking base of younger adults in rural communities. As the younger population leaves rural areas to seek employment opportunities in more urban settings, they take with them countless hours of family caregiving services. This change is especially problematic for rural people who value self-reliance and have traditionally depended upon family members for assistance during times of need (Bliezner et al., 2001). Therefore, strategies must be designed to reach an increasingly older target audience whose learning needs and styles are distinctly different from younger learners (Wilken, 2004). As caregivers age, they will also need additional assistance with physical care of the care receiver, transportation, and alternatives to home caregiving. Older caregivers of adult children with intellectual or developmental disabilities, many of whom they have cared for since birth, need strategies to help them plan for the time when they are no longer able to provide care.

Shortage of professionals. It is reasonable to expect that the critical mass of professionals will shrink as currently established professionals retire and are not replaced. This anticipated loss of professionals is one of the most critical issues facing caregivers and their communities in the future (HHS, 2003a). Even now, few specialists, particularly in the health-care field, are available to support caregivers in rural areas. Four primary outcomes result from this dearth of providers: (a) generalists perform as specialists, (b) mid-level professionals such as nurse practitioners and physician's assistants assume primary responsibilities for local health-care services, (c) paraprofessionals perform higher level duties than those for which they were trained, and (d) family members provide technical medical care for which they were never trained and are often uncomfortable performing (Guberman et al., 2005). Strategies to bring medical professionals to rural areas have met with mixed success (HHS) and depend heavily upon supportive policies such as medical student loan forgiveness programs and reimbursement schedules for health providers whose services are often undervalued by Medicare and Medicaid, the primary insurance providers for rural people.

Technology will offer solutions to some of these professional supply-and-demand issues (Korsching et al., 2003; Yellowlees et al. 2011). Telemedicine is defined by the Association of Telehealth Service Providers (2005) as "the provision of health care and education over a distance, using telecommunications technology." Telehealth technologies incorporate a range of technologies from the telephone or computer for information retrieval to the use of television monitors, video cameras with remote controls, video-conferencing, satellite communications, and streaming video via the Internet (see Yellowlees et al. chapter 2011).

Education and Training

Current Status

As the bulk of caregiving in rural communities increasingly falls upon the shoulders of family members and paraprofessionals, the need for additional training becomes evident. Paun et al. (2004, p. 248) noted that "skilled [sic trained] caregivers reported that training led to greater emotional acceptance and help[ed] them to analyze situations and modify their caregiving behaviors accordingly. … Skilled caregivers also maintained a broad approach to self-care including mental, social, spiritual, and physical approaches." Community colleges and vocational training provided through high schools, community centers, and local long-term care facilities strive to meet the training needs for paraprofessional caregivers, particularly nurse aides and home health aides.

These educational institutions are making effective use of distance education modalities to provide support for students living in rural communities. The State of Kansas, which had recently privatized home-care services, funded a distance education program to prepare paraprofessionals for dual certification as nurse aides and home health aides. This program was jointly sponsored by a coalition involving Kansas State University, the Kansas Department of Social and Rehabilitative Services, and several long-term care facilities and resulted in the training and certification of nearly 300 women who were tied, for personal and family reasons, to their rural communities (Wilken 2005, personal communication).

Future Trends

There are a number of promising programs and innovative distance and continuing education opportunities for rural caregivers worthy of expanding into many rural areas. Developed by Cooperative Extension and Area Agencies of Aging, the *Healthwise for Life* curriculum is one replicable way to get health education into communities via extension offices, and caregivers in Colorado, Delaware, and Virginia have benefited from the *Healthwise* curriculum (Delaware Health and Human Services, 2003). *Breaking New Ground Resource Centers* were designed by Cooperative Extension faculty at Purdue University to support caregiving for farmers with disabilities (Jones & Field, 2005). Aside from traditional education, expanding a community program such as the *Gatekeeper Program* supports caregiver individuals who could provide indispensable information about caregivers in distress. The *Gatekeeper Program* trains volunteer community members, such as postal workers, bank tellers, utility workers, and many other employees in customer-contact jobs to recognize people (mostly older adults) on their routes who are in need of assistance (Illinois Department of Aging, 2004).

Demographers predict a rise in the number of Hispanic and African-Americans needing care (HHS, 2003a). Caregiver education and training must address the diversity of caregivers as well as those needing care through the development and implantation of culturally sensitive curricula and materials (Eaves, 2002). It is also necessary to identify professional caregivers who are culturally competent. In rural communities, culturally competent professional caregivers will understand family systems and caregiving norms of the minority ethnic group, have language proficiency, and develop instructional materials that are culturally sensitive. Cultural accommodations are fairly available in urban areas, where enclaves of ethnic groups reside. Caregiver education that encompasses the cultural needs of the changing demographics of rural America is essential because new generations of hyphenated, rural Americans will require information about caregiving.

Research

Current Status

Information about rural caregivers and their needs. Entering the twenty-first century, little was known about caregivers and caregiving in rural America (Cueller & Butts, 1999). The survey research of demographers currently provides important data regarding the distribution of the population in rural America, because the changing demographics of rural communities play a key role in the types of strategies that can be utilized to support rural caregivers. The shrinking rural population base correlates with fewer resources, both human and financial, and will result in an ever-increasing need to find ways to use those resources efficiently and effectively. Research addressing the needs of rural caregivers must take into account the diverse nature of caregiving and the wide range of strategies used to support rural caregivers. Obstacles to research in rural America include distance, funding, diversity, sample size, access to samples, gatekeeping, privacy issues, and lack of research personnel.

Program evaluation research. Support programs implemented for rural caregivers must be theoretically sound, research-based, and their effectiveness with rural audiences empirically tested. It is well known that research with a rural focus is inherently difficult due to logistics related to travel, the accessibility of a sufficient sample, and costs. Empirically evaluated caregiving programs designed for rural audiences are difficult to identify, but a few examples exist. Weston (2005) described the use of Schon's (1988) strategy of reflective practice to evaluate training for caregivers in infant mental health. Qualitative content analysis of caregiver interviews was used by Paun and colleagues (2004) to measure the effectiveness of an Alzheimer's caregiver training program. Traditional course evaluation using e-mail, phone, and fax surveys to contact participants in the National Family Caregiver Support Program titled CARES (Caregiver Adaptations to Reduce Environmental Stress) was delivered to para-caregivers on-line (Sabata et al., 2005).

Grandparents raising grandchildren. An ever-increasing group of caregivers needing research-based interventions include the more than 4.5 million households that contain grandparents who are raising their grandchildren (AARP, 2004). Many of these skipped-generation families are families of color, living in the South, in predominantly rural communities (Bullock, 2004). In spite of the recent attention given to grandparents raising grandchildren in the literature and the media, there is a significant lack of data on strategies to support grandparents (Bullock, 2004). Researchers have confirmed the relationships between kinship care and such things as housing problems (Fuller-Thomson & Minkler, 2003), role confusion (Dellmann-Jenkins et al., 2002; Hayslip et al., 1998), parenting (Landry-Meyer, 2000), children with special health-care needs (Farmer et al., 2005), and legal concerns (Albert, 2000).

A wide variety of strategies have been developed to support grandparents raising grandchildren. While some anecdotal evidence suggests that support groups may lessen some of the stresses and burdens of providing full-time care for grandchildren, they often simply provide an opportunity to express their frustrations to fellow grandparents (Strom & Strom, 2000). Groups that make education a primary focus have been successful in decreasing negative affect scores, financial strain, and depression while increasing parental self-efficacy and the quality of the relationship with the grandchild (Hayslip, 2003). Participation in *Kinship Care Connection*, a school-based psychosocial intervention, led to increased self-esteem in children and mediated kin caregiver burden (Strozier et al., 2004). Further research is needed to investigate the role of such interventions with rural grandparents and their grandchildren.

Telehealth and telemedicine. Successful telehealth programs address issues associated with access to services, education, respite, and other caregiving resources that are influenced by the distance required to travel to receive services (Kobb et al., 2003). Telehealth and telemedicine have proven effective in bridging the distance between rural caregivers and the information and support they need (Sullivan, 2008). Patient and provider satisfaction with telehealth technologies is high because such programs meet the needs of patients, families, and providers (e.g., Buckley et al., 2004; Kobb et al., 2003).

Future Status

Future research to support rural caregivers must include assessments of current and projected caregiving support needs as well as empirical, evaluation studies of both well-established caregiving support programs and new, innovative programs and services (Wilken et al., 2001). Researchers must develop research methodologies and data collection techniques that are sensitive to the unique stresses of caregiving, such as conducting face-to-face interviews in the caregiver's home or scheduling telephone interviews at a time convenient to the caregiver. Geographic information system (GIS) tools are a new technology to support research. GIS data can be used to describe the accessibility of services and strategies in a given region. The Center for Rural Health Research and Education (CRHRE) in Wyoming emphasizes this form of data collection and the use of GIS to determine accessibility to services (Center for Rural Health Research and Education n.d.). Graphic Information Systems, as a research method, will contribute to our understanding of caregiver's patterns of service usage and contribute to the design of better strategies of support for caregivers, particularly as to where to locate support services.

Policy and Advocacy

Current Status

Three policy issues come to the forefront for today's rural caregivers. First, the changing face of rural populations has brought attention to the lack of diversity among health-care providers in rural America. Next, states are creating policies and programs designed to provide specialized training to all kinds of caregivers. Lastly, mental health professionals are establishing comprehensive mental health supports and services for rural residents and caregivers.

In 2000, the rural population was 69.1% Caucasian and 30.9% non-Caucasian, and by 2020 demographers predict the rural population will likely be 60.8% Caucasian and 39.2% non-Caucasian (Office of Rural Health Policy, 2003). Fewer physicians and health-care professionals of color will be available to serve the caregiving needs of non-Caucasians. So rural communities already designated as physician shortage areas will likely not have access to health-care professionals of similar culture or ethnicity. Though researchers and health-care professionals express the need for diversity in caregiving, it is a relatively new policy issue still gathering momentum.

The shortage of trained professional and paraprofessional caregivers in rural areas is, however, receiving attention from decision makers. State education policy in a few states has incorporated the community caregiving needs with technical or vocational education curriculums. The 2002 report authored by North Dakota State/University of North Dakota identified several new paraprofessional training programs. The *School to Career Pathway* in Colorado, the Wisconsin *Youth Apprenticeship Program* and the Massachusetts program, which allocates state scholarships for students pursuing a career in health care, are examples of proactive policies designed to increase the supply of health-care providers. Similarly, California has spent $25 million on the *Caregiver Training Institute* to educate caregivers (NDSU & NDU, 2002). Education policy is beginning to address the instructional and professional needs of rural caregivers.

Policies focused on supporting rural caregivers of persons with mental health concerns are critical as caregivers of the mentally ill lack support and services, particularly in rural America. Depression ranks second, behind ischemic heart disease, as a leading source of disease burden in established market economies of the world (National Institute of Mental Health, 2001). Persons suffering from mental illnesses, including schizophrenia, bipolar disorder, and posttraumatic stress disorder require caregiving support. The NRHA (2004) estimates that *20% of rural counties lack mental health services versus 5% of urban counties*. In 1999, 87% of the 1,669 Mental Health Professional Shortage Areas in the United States were in rural counties, amounting to 30 million people underserved (NRHA, 2004).

Despite the shortage of mental health professionals, the need for mental health services seems to be great given that the suicide rate among rural men is higher than in urban areas, particularly among adult men and boys. The suicide rate among rural women is increasing and is expected to reach the same rate as rural men. The documented lack of services and mental health professionals, and the need for more mental health outreach plus the oft-cited stresses associated with caregiving have created a very potent environment for a mental health crisis to grow. While the need for action is evident, policies to nurture the growth of mental health systems and include the needs of caregivers in rural America are still in their infancy (NRHA, 2004).

Federal, state, and local policies can enhance the lives of rural caregivers through strengthening the capacity of local communities to provide services and support. Strengthening local capacity includes establishing policies to insure the local availability of health-care professionals at all levels of training, creating a convenient and comprehensive transportation system, offering affordable and functional housing, economic development promoting employment opportunities designed to keep younger generations from leaving their rural communities, accessible and meaningful training and services for family caregivers, and financial support to defray the costs of providing care. An examination of policies directly related to transportation, housing, and economic development are beyond the scope of this chapter.

Until recently, public policy, particularly at the federal level, has been nonresponsive to the service needs of caregivers. The National Family Caregiver Support Program (NFCSP), funded through the Older Americans Act (OAA) Amendments of 2000, was the first federally funded program implemented at the state level to support the service needs of older people (Feinberg & Newman, 2004, p. 760). This program, designed to meet the needs of family caregivers rather than the care recipient, was a dramatic paradigm shift for governmental agencies whose programs have traditionally focused on the direct need of the care recipient as opposed to serving the care receiver by providing assistance to the family caregiver. The NFCSP proposes to support family caregivers in five ways, by offering: (a) information about available services; (b) assistance to caregivers in gaining access to services; (c) individual counseling and support groups, (d) respite care; and (e) supplemental services, such as home modifications (HHS, 2003b).

Although this program is an important first step to supporting all caregivers, central issues related to rural life impact the ability of this policy to serve as a strategy to support rural caregivers. It is imperative that this policy allow for flexibility in implementation at the local level where "information about services" may translate into information about the "lack" of services, and "access to services" is not an issue when those services, such as individual counselors or support groups, do not exist. Policy makers must understand and respond to the needs of rural caregivers. Medicaid waivers that allow states to utilize Medicaid dollars to respond to localized needs are but one example of policy responding to local needs. Those states that have granted Medicaid HCBS-waiver programs to allow family caregivers to be paid for their services (Feinberg & Newman, 2004), tax credits to help rural caregivers purchase necessary home repairs and renovations to support their caregiving, and stipends for purchasing caregiving-related equipment reflect the spirit of the NCSP and offer a model of the flexibility needed by rural families who depend on family caregivers to forestall or prevent institutionalization.

Future Trends

Policy makers must consider the current and future diversity of rural America. Do current programs and services meet the needs of rural caregivers? Are they adaptable to meet the future needs? In essence, will rural caregivers have access to services sensitive to the needs and wants of minority groups? Caregiving advocates must raise awareness about diversity and the necessity of developing culturally competent policies and programs (Eaves, 2002).

Opportunities for continued collaboration and partnerships to develop strategies to support rural caregivers should be part of any policy discussion. For example, rural hospitals and related caregiving agencies in West Virginia, Montana, and Kansas have developed networks to eliminate overlaps and gaps in caregiver support (Office of Rural Health Policy, 1999). These networks involve formal collaborative agreements between agencies and an ongoing communication strategy that keeps each member of the network informed about local programs and needs. Policies for rural caregivers should continue to seek collaborative relationships and encourage new partnerships whenever possible.

Increasing policy emphasis on the lack of mental health services in rural areas and its implications for rural caregivers needs to be seen as a specific issue in future public policy (HHS, 1997). Policies should be enacted to use or expand already existing telehealth delivery systems for mental health services and consultations, eliminating the barrier of distance, shortage of qualified mental health personnel, and some of the stigma attached to seeking mental health services. While telehealth can provide convenience and privacy, more mental health professionals also need to be placed in rural areas and be a direct part of any strategy to support rural caregivers (e.g., Bliezner et al., 2001). The accessibility of mental health professionals and services are often a lifeline for any caregiver, but more so for rural caregivers. New policy must reflect their special circumstances.

Dwindling numbers of people, smaller tax bases, and fewer advocates for caregivers in rural America are barriers to realizing all the progressive policy initiatives needed to support rural caregivers (Gibson, 2005). Additionally, the incremental nature of policy making means that while policy changes can be made to better support rural caregivers, it is often a slow and lengthy process. Future policy will need to address many aspects of rural life and service delivery in order to successfully find strategies to support rural caregivers.

Summary

Strategies that successfully support rural caregivers respect the unique nature of providing care in a rural community. To work successfully in a rural environment, program planners, researchers, and policy makers need current and reliable data describing the caregiving population. This is especially necessary with increasing diversity and the phenomenon of out-migration of younger adults from rural regions of the United States. Additionally, information and data about specific needs of caregivers and an inventory of resources and services need to be collected. With this information, all involved in formal and informal caregiving will have an accurate knowledge base from which to plan programs and interventions, and to make larger policy decisions.

In addition to collecting more information about rural demographics and the needs of caregivers, formal and informal services for caregivers must attend to specific needs as opposed to general, one-size-fits-all approaches. The same is true with the availability of services and professionals; offering an array of qualified professionals, specialized facilities, and a various services should be part of any support strategy for caregivers. Programs and services must address the needs of rural caregivers, factoring-in financial, housing, and transportation issues. Professionals and service providers need to work within the existing infrastructure of rural communities. This means using local professionals, program sites and facilities, organizations, and caregivers themselves when developing and designing support strategies for rural caregivers. In this way, rural communities are integrated into the support strategy in a way that builds on local resources rather than dwelling on limitations within the community.

Support strategies should also take into account the unique aspects of rural culture. Working in rural areas of America presents ethical concerns related to privacy, unlike in many suburban and urban locales. A caregiver outside rural areas might seek services anonymously or have great choice in where or from whom they seek services. This is not always an option in rural America. Any support strategy must remember how important privacy may be to rural caregivers and plan support strategies accordingly. Aside from privacy, rural communities are often characterized as self-reliant. In caregiving, this self-reliant quality often translates into dependence on the family to meet support needs. Taking into account the personality of rural America and its impact on rural caregiving will enhance most support strategies.

As we work toward support strategies for rural caregivers, great sensitivity and respect for rural culture and rural caregivers must be vanguard in the minds of program planners, researchers, and policy makers. Rural communities provide distinctive challenges to caregivers and those who try to support them. With appropriate programs and services, education for professional caregivers, relevant and applicable research, and informed and flexible policy, the needs of rural caregivers can be met.

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Chapter 12
State Responsibilities to Support Rural Caregiving: The Georgia Example

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A number of key factors that limit the quality and use of formal community-based services in rural communities are documented in the literature. These barriers include a lack of program funding, an inadequate workforce supply, the geographic distance between service-providers and clients, and caregivers' reluctance to use formal services and their lack of awareness and understanding about available services (Infeld, 2004; Morgan et al., 2002). Rural caregivers are less likely to use most formal services that might assist them in their caregiving efforts, supporting the overall observation that services are less available in rural areas (Easter Seals and National Alliance for Caregiving, 2006).

This chapter includes a brief overview of research findings obtained through focus groups and describes two innovative service delivery models developed which support the needs of rural caregivers.

A State Example: Georgia's Planning to Address Caregivers' Needs

Prior to the passage and funding of the National Family Caregiver Program (NFCSP),[1] the provision of services to caregivers was limited to incidental, small offerings, secondary to the direct services provided to care receivers. While aging professionals recognized the value of unpaid caregivers, state policy gave little

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[1] Incorporated into the Older Americans Act as the National Family Caregiver Support Program, Title III, Part E, through reauthorization in 2000.

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attention to their worth, health, and well-being. In anticipation of federal policy changes, Georgia policy makers began working with researchers, area agencies on aging, providers, and citizens to determine caregiver needs.

Throughout the planning phase, the needs of rural and isolated caregivers and care receivers were paramount, since 34% of Georgia's population aged 60 years and older live in rural areas (Georgia State Plan on Aging, 2008). Beyond the stark reality of the data, policy makers realized that the delivery of care in less populated areas is fraught with challenges, the most obvious of which is the limited availability of qualified, paid workers to travel the long distances to provide care. Concern for easy access and optimal self-direction by care receivers and caregivers influenced the implementation of all new or expanded programs.

During this period, Georgia also developed customer satisfaction tools and outcome measures, largely incorporating survey instruments and methodologies developed under the Administration on Aging's (AoA) Performance Outcomes Measurement Project (POMP). The valuable data collected through these trials has provided baseline data for customer satisfaction and for the adaptation and improvements of programs and services based on citizen and consumer input.

The paradigm shift for the aging network, which began with implementation of the National Family Caregiver Support Program, motivated the Georgia Division of Aging Services (DAS) to conduct focus groups to learn what family caregivers needed to maintain their loved ones at home, rather than trying to design programs and services based on second guesses.

Because of these and other efforts, Georgia's future for more self-directed care opportunities for families and individuals is unfolding. More people in rural Georgia will have the option to hire family members or friends to provide needed care, to obtain the goods and services needed to sustain the support system, and respite care through self-determination programs care in their communities.

Caregiver Focus Groups

Because the Division wanted data that reflected the actual experiences and needs of Georgia caregivers, it commissioned a consultant to conduct 11 focus groups across the state. The following information reflects the needs and perspectives of Georgia caregivers, as revealed through the focus group findings.

Research Approach

The focus group approach was used as the primary data collection method to explore the shared meaning of the everyday experiences of caregivers. The focus group team consisted of two persons who served as nonparticipant observers during sessions, a manager from DAS, and the consultant/moderator who conducted the focus groups.

Sample and Setting

Caregiver subgroups of diverse composition from 11 different locations were included in the focus groups in order to provide a wide representation of those giving care to older adults. Groups represented family members, paid professionals and paraprofessionals, and volunteers for a total of 123 participants. Participants ranged in age from 26 to 83 years, most (67.5%) were Caucasian, 27.6% were African American, and the large majority were female (86%).

Data Analysis

All focus groups discussions were audio-taped and transcribed verbatim, omitting any identifying information about participants. The group moderator conducted an analysis of the data, using a phenomenological methodology developed by Colaizzi (1978) and adapted by Scott (1993). Verbatim transcripts of the audiotapes, observation notes, and demographic data provided the basis for analysis. The data were analyzed first according to the respective individual caregiver groups. The data were then analyzed collectively across groups. Themes were organized based on common phenomena or experiences across groups. The essence of the sessions and the development of themes across groups were reviewed by other team member and one outside person for credibility purposes.

Focus Group Results

The overarching theme for the 11 groups was “Compassion Fatigue and Frustration,” extending from multiple, contextual perspectives. Compassion fatigue and frustration is best described as the constant state of weariness, frustration, and yet continuing willingness of the caregivers as they forged ahead to provide the care they perceived to be needed by the care receivers. The essence of this overarching theme is not entirely new to the caregiving literature (Hughes et al., 1999; Jones & Peters, 1992). However, a review of the other contextual factors provides more insight into how the six major themes of the study were shaped and how they also influenced the level of fatigue and frustration experienced by the caregivers.

Many other contextual issues compounded the frustration for these caregivers, including their beliefs about who “should” be responsible for care. Participants seemed to continuously look for an external source to blame for their frustration and the blaming and shaming included everyone from the churches, health-care professionals, and to the government. Others expressed their concern about health-care professionals not providing information that they needed to effectively manage their responsibilities. Although participants had provided care for varying amounts of time (3 months–20 years), they often perceived themselves as “official” caregivers only after a crisis event when physical care was needed; a belief that could serve as a guide and influence over effective interventions. “My mother is 94 years old and she lived by herself, and I would check on her everyday there about 9 years. [One day] she wasn’t in the house. We found her up the little dirt road. Well, the fire ants had eaten her up. So the EMTs came and got her and carried her to the hospital and since then we brought her to the house [and became her caregiver].”

Many of the participants in this study were providing care to more than one person. However, it was not just the numbers of persons they were caring for, but the variance in age of those persons, and the intensity of care required by each which compounded the difficulties of caregiving: “I care for my mother; she’s 100 last month. My husband’s got dementia real bad and I’m raising a special needs grandson. I had to take him [because] my daughter’s got cancer.”

Lastly, the caregivers’ own health also compounded the compassion fatigue and frustration seen so vividly in their stories. Many suffered from significant chronic diseases, such as diabetes, which were exacerbated by stress. Often they reported neglecting their own health-care needs. From these contextual factors emerged the overarching theme and the six major experiential themes.

Major Experiential Themes

The six major experiential themes describe the experiences across all subgroups represented in this study. While certainly variances were found, these themes reveal the similarities among the groups, and hence, provide data for developing appropriate interventions across groups.

Lack of Information and Coordination of Resources

Regardless of the duration of care provision, lay or professional status, or their extensive efforts, participants expressed their ongoing frustration around the difficulty locating information on different services. There were instances in which participants had heard about certain services but did not know exactly what they were, the reimbursement source, or how to locate them. Many suggested that the information or resource was often so obscure and hard to get to that it was not worth the effort it took. The lack of knowledge on the part of public agencies responsible for health care specifically was noted. Each participant shared their version of this theme and experienced varying degrees of related frustration. What was abundantly clear was how the lack of information and coordination of resources overwhelmed some individuals’ coping skills: “I think the hardest thing for me was finding help, competent help. That probably caused me more frustration that my husband did. The help was so bad. You had to have [the help], but to find competent [help]?”

Needs Exceed Availability

This second theme was couched in frustration and even a sense of impotence when needed services or resources were not available to the participants. This phenomenon was particularly true as it related to medications, transportation, and home care: “We had to admit 10 patients to the hospital strictly because they did not have their medicine to take because they couldn’t buy it.” Professionals noted hospital admissions that could have been avoided had people had the financial means to obtain medicines they needed.

A predominant undercurrent of this theme was the tension of caregivers knowing there were services available for which they or the care receivers qualified but, because of increased demand, they were often placed on a waiting list of unknown length and duration: “Being on the waiting list we need help now, we don’t need help 6 months down the road.”

Ageist Providers

“My mother complained that medical people, especially physicians, treat older people as though they were children condescending.” Ageism lurks in our society in different shapes and forms, including ignorance, apathy, and complacency. Ageism was strongly reflected in stories shared by each of the 11 group participants. No provider group escaped the assertion that persons working with older adults were not adequately educated, trained, monitored, or supported enough to take care of this population. Ageist providers were purported to increase the level of frustration and fatigue related to caregiving. Some participants tread lightly over the topic and others were very assertive in expressing their anger. Condescending or patronizing attitudes of providers toward elderly individuals was noted, as well as a concern that both professional and paraprofessional health-care providers lacked adequate knowledge, particularly in the area of dementia care. Lack of adequate training and lack of respect for nursing assistants providing respite care by employers was noted as a cause of poor quality in care provided.

The Lone Caregiver

Being the “Lone Caregiver” was related to the perspective that there was no one else to be the caregiver or to provide assistance with caregiving responsibilities. In some cases, they were in fact the only family member with no children or siblings to assist. In other situations, the participants had “potential” assistance from various sources. However, paid and nonpaid participants did not see that others were available or accessible to them for various reasons. Others stated lack of funds often prohibited others’ involvement.

Pushing Against the Tide

In addition to feeling like the "Lone Caregiver," participants expressed the belief that others misunderstood their actions, in the role of caregiver. Regardless of what care was provided, some participants felt like they were judged for "doing too much." They particularly noted the frequent advice by health-care providers to institutionalize their family member. Conversely, other participants suggested some perceived them as not doing enough or that caregiving for an older adult was not understood as significant as other "jobs."

"People think you're just at home all the time. You are not doing anything and you haven't used very good judgment." Some of the participants described this lack of validation for their role as "pushing against the tide."

Living a Dilemma

The last of the six themes from this study spoke of the many dilemmas confronting them throughout the caregiving experience which they felt forced them to make choices between equally unsatisfactory actions. These choices or decisions may have related to what were a perceived safety issue and an individual's choice, for instance, deciding where care is to be provided and by whom. In other situations, the dilemma revealed itself in the stress of deciding whether to have a nursing assistant in the home. While respite was sorely needed, having outside assistance was more often than not perceived as more exhausting or doing more harm than it was worth: "Another thing you gotta watch them all the time. I warned her NEVER to leave that door unlocked. Now the door was open and the first thing you know he fell. He broke his arm."

Discussion of Focus Groups

The data from this study come directly from Georgia caregivers and, therefore, is unique relative to their experiences and the resources available to them in this state. From the overarching theme of "Compassion Fatigue and Frustration" and the multiple contextual factors from the everyday lives of these caregivers, the six emergent experiential themes are consistent with what is often found in the caregiving literature (Hughes et al., 1999; Pedler & Biegal, 1999). The themes, however, also added more depth and declaration to what these caregivers experienced, offering a broader understanding of caregivers in the state. Moreover, the documented data provided a framework for leaders, legislators, and providers to fund, design, and deliver the most appropriate and effective support to those who are caring for our older citizens. While the data cannot be generalized, it does provide potential insight into the experiences of other caregiver groups and can be used to inform the practices of various caregiver subgroups that offer service interventions.

Because of the dearth of health-care providers in the rural areas and more specifically health-care providers trained or educated in gerontology, caregiving for older adults more often falls on the family members. Hence, many of the recommendations related to specifically assisting the caregivers. Among many other recommendations, the top recommendations included: (1) having more coordinated information on services and providers to provide less time-consuming access; (2) more services with a particular emphasis on home respite care in the evenings and weekends; (3) financial assistance to assist in actually procuring those services that were available to them; and (4) more adequate training for providers at all levels to diminish the concern and frustration of leaving their loved ones in the care of those they felt inadequately prepared.

Current Status and Future Directions

The data from this focus group study are consistent with other caregiver research. The major themes and the recommendations generated by the caregiver participants also raise important questions and suggest the need for further study. The data in this study strongly suggested that how the primary caregiver perceived others involved in the process significantly influenced caregiver stress. Further exploration could assist in confirming this finding and assist in determining how to address the phenomenon.

Nursing assistants are one of the largest caregiver groups for older adults and also have a very high turnover rate in long-term care. Further qualitative and quantitative study is needed to determine what is needed to assist them to do their best work and what factors would keep them in their positions. Data of this nature would inform all groups involved in the caregiving process. Lastly, more study is needed to determine the cost-efficiency and cost-effectiveness some of the different program modifications recommended. For instance, does offering weekend and evening/overnight respite significantly reduce caregiver burden for those living in rural areas?

Mobile Day Care

Focus group participants specifically identified the need for more respite services (Scott, 2002). For many, respite care was not available in their community in any form. In response, Georgia expanded both its in-home respite programs and developed the Mobile Day Care (MDC) program to expand the availability of respite care to more of its 159 counties.

Mobile Day Care (MDC) is an innovative service delivery model that enables rural communities to have their own day care program by sharing staff who travel among several rural counties each week. Though the term *mobile day care* conjures images of a facility that moves, it is actually the staff, along with materials and supplies needed for the day that are mobile. Depending on the needs of the community, sites may be open for 5–6 h per day, 1–3 days each week. Staff travel to at least two different communities each week. Space for MDC is frequently located senior centers, though church facilities also may be utilized. The particular advantages of using space in senior centers are as follows:

- Use of the center is a cost-effective alternative to the traditional "bricks and mortar" facility-dependent service since there are no construction costs. Utilizing existing facilities has proven to be an important factor in the program's success at a time when financial resources for start-up expenses are limited or nonexistent.
- Though the MDC program is new to a community, by partnering with the senior center, immediate credibility in the community is established, which has been found to be critical to success.
- MDC provides access to services for persons whose increased functional limitations render them no longer appropriate to attend the senior center.
- MDC programs provided from noon to 5 p.m. can make use of space in a senior center which may be is underutilized, due to site activities taking place primarily earlier in the day.
- The MDC program can purchase meals from senior center.
- MDC clients can enjoy interaction with other seniors in jointly conducted activities.
- Volunteer recruitment is enhanced by the association with a familiar, trusted entity.

While a number of Georgia's 159 counties have senior centers, some of the constituent municipalities or communities do not. In such cases, locating the MDC program in a faith-based setting such as a church, synagogue, or mosque may be a highly viable alternative.

Benefits and outcomes produced through establishing MDC include:

- Providing caregivers in previously unserved areas some level of respite support
- Helping to retain more highly trained staff because of flexibility with part-time and full-time positions
- Viability in serving rural counties or the neighborhoods of a large metropolitan area
- Building trust and credibility in the community; by establishing a community coalition, MDC brings together individuals and organizations that have previously not worked together
- Increasing the use of respite as family caregivers become more accepting of and willing to use services; MDC can actually be a precursor of full-time day care as the demand for and use of respite services can actually increase
- Recognizing the program as a best practice worthy of replication, as referenced in a number of public policy reports and publications (Gamm & Hutchison, 2004; Montgomery, 2002)

Current Status and Future Directions for Mobile Day Care

Research has shown that respite is one of the most needed and valued services that can be provided to family caregivers (Fox-Grage et al., 2001). At the time when the nation is experiencing a dramatic increase in the number of persons over aged 65, the number of family caregivers continues to decline due to decreasing birth rates, decreasing family size, increasing geographic mobility, and the increasing number of women in the workplace, for example. The need for respite services including models such as mobile day care, therefore, continues to increase. In an economy where resources become increasingly scarce, more states should explore the feasibility of opening mobile day care programs in senior centers and faith-based facilities which enable multiple communities to benefit from respite without the investment in "brick and mortar facilities," both for non-Medicaid-funded services and Medicaid-waivered programs.

The Louisiana Governor's Office of Elderly Affairs has started a Mobile Day Care program using the Georgia model, operating in two rural areas that previously were without day care or other respite services. The demand in response to the program and sustained enrollment demonstrates that the program can be successfully replicated in other states and regions. Additionally, Georgia's Community Care Service Services Program, a cost-effective alternative to nursing home placement for Medicaid eligible consumers that maintains the consumer at home, has added Mobile Day Care to its array of services.

If funding for new programs such as Mobile Day Care are limited or otherwise not available, states may also consider providing education to groups such as the faith community, teaching congregations how to provide models of respite care for their own congregants and the community at large. Once the education sessions are provided, the faith communities implement and fund these programs using their own financial resources. Georgia, in partnership with the Georgia Chapter of the Alzheimer's Association, is funding such a program, called Congregational Respite.

Consumer-Directed Care

Another innovative service delivery model that grew out of Georgia's focus group recommendations and that has proven particularly effective in rural areas is consumer-directed care. Consumer-directed care, often referred to as self-directed care or self-determination, is a service model which supports consumers in assessing their own care needs, choosing how and by whom those needs will be met, and evaluating the quality of services received (Nadash, 1998). Some programs increase consumer control further by providing cash benefits and allowing beneficiaries to purchase their own services or pay caregivers, including family members, friends, and neighbors. In rural areas where consumers have access to a smaller number and more narrow range of community-based services, the option of hiring family, friends, and neighbors, fill important service gaps in these communities and supports and addresses an important cultural value – that of self-reliance (Infeld, 2004; Morgan et al., 2002).

Advocates, including an increasing number of policy makers and aging services providers, view consumer direction as a relatively safe and potentially cost-effective way to allocate limited resources and deliver care (Stone, 2000). As the shortage of frontline workers available to deliver long-term care across all care settings increases, some view consumer direction as a method to promote more flexibility in hiring workers, including family members (Feinberg et al., 2006). Despite its growing popularity as a service model, numerous opponents express concerns regarding quality assurance, liability and abuse, and misuse of funds (Kodner, 2003; Young & Sikma, 2003). Recent studies, however, show no evidence that consumer-directed models of service provision are any riskier than traditional agency-managed services (Kunkel et al., 2003–2004; Tilly et al., 2000). On many outcome measures, including measures of client satisfaction and service quality, these studies find that consumer-directed models outperform agency-based models.

The Georgia Division of Aging Services was awarded a 3-year grant from the Administration on Aging (AoA) to develop a consumer-directed care demonstration project. The primary goals for the project were to increase service options for Georgia's elderly population, a large percentage of who live in rural areas, and to develop consumer-directed care models that can be replicated in other states. From the outset, we were interested in data that could be used to guide policy development and educate program planners and service providers.

Project Background

The Georgia Demonstration Project targeted older adults with dementia and their caregivers. Five Area Agencies on Aging (AAAs) were selected to implement the program. Caregivers had the option of selecting the range of services that best suited their needs. AAAs provided consumers with access to both traditional and nontraditional service providers. Three AAAs developed a component through which consumers had the option of hiring relatives or friends to provide services, a choice that proved particularly useful for those in rural areas who had less access to traditional service providers.

These services ranged from hiring a neighbor, friend, or licensed agency to provide personal care or perform errands, to the purchase of consumable supplies, such as nutrition supplements, over-the-counter medications, disposable gloves, and incontinence supplies. In general, programs provided up to $1,200 per year for caregivers hire persons for personal care services and an additional $600 for consumable supplies.

To the extent possible, caregivers and care receivers were involved together in the decision making of this program. The program also included a care manager component. In addition to mentoring consumers about funding and payment options, care managers maintained monthly contact with consumers and provided continuing education regarding available programs and services. A challenge of the program was providing consumers with adequate education without making the program seem overly complicated. To assist with this task, an expert in consumer-directed care legal and financial aspects of the program provided information to AAA staff and/or provider care managers and guided them in educating family caregivers.

Methods

Over a 16-month period, researchers at the Gerontology Institute at Georgia State University conducted telephone interviews with self-directed caregivers using a modified version of the *Caregiver Support and Satisfaction Surve*y, an instrument used by states participating in an AoA initiative known as the Performance Outcomes Measurement Project (POMP). The structured 67-item questionnaire includes both close-ended and open-ended questions. Questions address a wide range of topics including but not limited to: demographic information about the caregiver and care receiver, the types of services coming into the home, satisfaction with services received, information needed by caregivers, kinds of assistance provided by caregivers to care receivers, positive and negative effects of caregiving, and the effects of caregiving on work status. Six questions were added to this instrument, which specifically addressed services received through Georgia's Self-Directed Care Program.

Eligible respondents were those caregivers who had been enrolled in the demonstration project for at least 6 months. Of the 136 caregivers contacted by telephone, 128 completed surveys, a 94% response rate. Surveys lasted from 10 min to 75 min, with a mean of 33 min.

Responses from self-directed caregivers were analyzed and compared with responses from 1,301 POMP caregivers who received services through the traditional service delivery system. The POMP sample was drawn from clients of caregiver programs in six states: Florida, Georgia, Illinois, Indiana, New York, and North Carolina. Of those 1,301 caregivers, who received services through the traditional service delivery system, 372 were drawn from programs in Georgia.

Researchers used bivariate analyses (chi square and t-tests) to compare caregivers who participated in the Self-Directed Care Program with POMP caregivers on sociodemographic variables, perceived burden, and service outcome measures by geographic location (rural vs. urban) and service type (consumer directed vs. traditional agency based). To determine geographic location, researchers used a classification system commonly referred to as the "Beale codes," based on data from the 2000 census. Using this classification system, they coded participants' county location along a nine-point continuum (1 = *metropolitan counties with an urban population of 1,000,000 or more*; 9 = *completely rural areas with populations of 2,500 or less*). For the purposes of this analysis, they collapsed these codes into two categories labeled "urban" and "rural." They coded counties with populations of 19,999 or less "rural" and all counties with populations of 20,000 or more "urban."

Researchers also used content analysis to identify consistent themes in the data from open-ended questions which addressed caregivers' attitudes about service provision and the positive and negative effects of caregiving.[2] For purposes of this analysis, data were sorted and analyzed by geographic location (rural vs. urban).

Results

Table 12.1 presents the sociodemographic characteristics for self-directed caregivers by geographic location: 73 caregivers (57%) lived in rural areas, close to half (46%) were African American, and 40% of these minority caregivers lived in rural areas. As might be expected, rural caregivers were significantly more likely to be less educated and have a lower annual income than urban caregivers. More than half (59%) of rural caregivers had a high school diploma or less, compared to 33% of urban caregivers. The mean annual household income for rural caregivers was between $10,701 and $13,850, compared to urban caregivers, whose mean annual household income was between $18,251 and $25,000. Other than education and income, no other sociodemographic characteristics were significantly different between the groups (see Table 12.1).

Table 12.2 summarizes the sociodemographic characteristics for caregivers by geographic location and caregiver program. Compared to urban POMP caregivers, urban self-directed caregivers were significantly more likely to have some college education, live with the care recipient, and provide a higher proportion of care. Like their urban counterparts, rural self-directed caregivers also provided more care and were more likely to live with the care recipient compared to rural Pomp caregivers. Only one finding was significant for care recipients. Rural care recipients who were enrolled in the Self-Directed Care Program were more likely to be male than POMP care receivers in the same geographic category (see Table 12.2).

Table 12.3 compares caregivers' burden ratings for five items by geographic location and caregiver program. Responses were scored using a 5-point Likert-type response scale (1 = *always*; 5 = *never*). T-tests revealed statistically significant differences between self-directed caregivers and POMP caregivers. Where lower mean scores signify greater burden, compared to POMP caregivers in both groups, self-directed caregivers in both groups reported that their caregiving duties more often burdened them financially; left them with not enough time to care for themselves or the rest of their family; affected their relationship with other family members in a negative way; interfered with their personal needs for privacy; created problems in their social lives; and created stress. Compared to urban POMP caregivers, urban self-directed caregivers also reported that caregiving more often interfered with work. Data from open-ended questions supported these findings. Key themes included stress, depression, isolation, loneliness, and lack of personal time ("being tied down") (see Table 12.3).

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[2] Researchers did not have data from POMP caregivers. Only data from self-directed caregivers were analyzed.

Table 12.1 Descriptive characteristics for self-directed care clients by geographic classification

		Rural ($n=73$)	Urban ($n=55$)
Caregiver			
Gender%			
Female		82.2	87.3
Male		17.8	12.7
Kin relationship%			
Spouse		37.0	30.9
Daughter		45.2	47.3
Lives with care recipient%		84.9	90.9
Married (spouse still living)%		69.9	52.7
Race%			
White		60.3	56.4
African-American		39.7	41.8
Education%			
Some college or more		41.4	67.3*
High school diploma or less		58.9	32.7*
Work status%			
Working at least part-time		27.4	32.7
Not working		72.6	67.3
Health affects care		38.4	34.5
Caregiver age (years)	M	60.9	61.3
	SD	13.2	13.0
Household income	M	4.6	5.9**
(1 = < than $5,000; 9 = $50,001 and up)	SD	2.2	2.4
Proportion of care	M	5.1	5.3
(1 = a little; 6 = all)	SD	1.2	0.8
Care recipient			
Gender			
Female		65.8	69.1
Male		34.2	30.9
Age (years)	M	79.5	80.8
	SD	8.6	8.6

A t-test is used for age, annual household income, and proportion of care provided. A chi square statistic is used for all other variables
$^{*}p<0.05$; $^{**}p<0.01$

Table 12.4 presents caregivers' satisfaction ratings for three items by geographic location and caregiver program. Compared to rural POMP caregivers, rural self-directed caregivers were significantly more satisfied with overall services and more often reported that these services enabled them to provide family care for a longer time period. Analysis of responses to open-ended questions showed no unique group differences (see Table 12.4).

Key themes that emerged for both groups were that the program (a) provided financial relief; (b) helped prevent nursing home placement; (c) gave physical and emotional relief; and (d) increased the ability to provide better care. Before enrollment

Table 12.2 Descriptive characteristics for self-directed care clients and POMP clients by geographic classification

		Rural ($n = 354$)		Urban ($n = 968$)	
		POMP ($n = 281$)[a]	SDC ($n = 73$)	POMP ($n = 913$)[a]	SDC ($n = 55$)
Caregiver					
Gender%					
Female		68.7	82.2*	72.2	87.3*
Male		31.3	17.8*	27.8	12.7*
Kin relationship%					
Spouse		26.4	37.0	25.5	30.9
Daughter		40.4	45.2	37.0	47.3
Lives with care recipient%		64.4	84.9**	62.8	90.9***
Married (spouse still living)%		66.3	69.9	63.3	53.7
Race%					
White		69.7	60.3	66.9	56.4
African-American		29.2	39.7	29.1	41.8
Education%					
Some college or more		34.3	41.1	45.2	67.3**
High school diploma or less		65.7	58.9	54.8	32.7**
Work status%					
Working at least part-time		35.0	27.4	33.9	32.7
Not working		65.0	72.6	66.1	67.3
Health affects care		38.2	38.4	38.7	34.5
Caregiver age (years)	M	60.8	60.9	61.7	61.3
	SD	14.1	13.2	14.0	13.0
Household income	M	5.2	4.6	6.1	5.9
(1 = < \$5,000; 9 = \$50,001 and up)	SD	2.5	2.2	2.2	2.4
Proportion of care	M	4.3	5.1***	4.3	5.3***
(1 = a little; 6 = all)	SD	1.3	1.2	1.3	0.8
Care recipient					
Gender					
Female		77.9	65.8*	73.9	69.1
Male		22.1	34.2*	26.1	30.9
Age (years)	M	80.2	79.5	81.1	80.8
	SD	10.5	8.6	9.9	8.6

[a] Due to missing information, total N (1,301) is not represented here

A t-test is used for age, annual household income, and proportion of care provided. A chi square statistic is used for all other variables

$^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$

in the program, many caregivers reported that they were struggling to purchase needed supplies, such as incontinence products. Without the support to buy these items, several caregivers said that they might have been forced to place their loved ones in a nursing home. One rural caregiver said, "[The Self-Directed Care Program]

Table 12.3 Caregiver burden by geographic location and caregiver program

	Rural ($n=354$)		Urban ($n=968$)	
	POMP ($n=281$)[a]	SDC ($n=73$)	POMP ($n=913$)[a]	SDC ($n=55$)
Caregiver burden	M (SD)		M (SD)	
Financial burden	3.68 (1.4)	3.08 (1.5)**	3.66 (1.4)	3.00 (1.4)**
Lack of time for self	3.18 (1.4)	2.60 (1.4)**	3.11 (1.4)	1.98 (1.1)*
Lack of time for family	3.50 (1.4)	2.87 (1.5)**	3.50 (1.4)	2.37 (1.3)***
Interferes with work[b]	3.93 (1.0)	3.36 (1.5)	3.64 (1.1)	2.78 (1.4)**
Negatively affects family relationships	4.32 (1.1)	3.53 (1.6)***	4.12 (1.2)	3.40 (1.5)**
Interferes with privacy	3.93 (1.4)	3.18 (1.6)***	3.78 (1.4)***	2.58 (1.4)***
Creates problems in social life	3.84 (1.5)	3.06 (1.7)***	3.64 (1.5)	2.60 (1.5)***
Creates stress	3.07 (1.4)	2.63 (1.4)**	3.01 (1.3)	2.33 (1.3)***

[a] Due to missing information, total N (1,301) is not represented here

[b] Applies to caregivers who work at least part-time

A t-test statistic is employed to establish significant differences

Responses are scored using a 5-point Likert scale (1 = always; 5 = never)

$p<0.05$; $^{**}p<0.01$; $^{***}p<0.001$

Table 12.4 Service outcome measures by geographical location and caregiver program

	Rural ($n=354$)		Urban ($n=968$)	
	POMP ($n=281$)[a]	SDC ($n=73$)	POMP ($n=913$)[a]	SDC ($n=55$)
Service outcome measures%				
Increased overall service satisfaction	67.0	83.6**	67.3	80.0
Enhanced caregivers' ability to provide care	79.3	86.3	77.5	85.5
Extended the time period for family care	61.5	76.7*	63.6	69.1

[a] Due to missing information, total N (1,301) is not represented here

A chi square statistic is employed to establish significant differences

$^{*}p<0.05$; $^{**}p<0.01$

has been helpful with supplies. I am very grateful. I am trying to keep her [the care receiver] at home desperately." Respite was another service highly valued by caregivers. Many said that the respite they received through the program relieved physical and mental stress and enabled them to provide better quality of care. This statement by a rural caregiver reflects a common attitude held by many: "Ability to take a break relieved some of my stress and made me better to Mama."

Discussion

Rural caregivers who were enrolled in Georgia's Self-Directed Care Program represent a highly vulnerable group. Compared to caregivers in other categories, they were more likely to be low-income, have lower levels of education, and experience significant caregiver burden. Although no significant racial differences were found between the groups, more than one-third (39.7%) of rural self-directed caregivers were African American. As their age increases, these minority caregivers are at greater risk of poverty and poor health than their White counterparts (Coward et al., 1998; Roff & Klemmack, 2003). Each of these findings has serious implications for the quality of care of Georgia's rural elders.

Previous research indicates that rural elders are "over-institutionalized," often due to an inadequate supply of community-based services and the greater relative availability of nursing home beds (Krout, 1998). Findings from this evaluation show that rural elders may be at greater risk of institutionalization than elders living in urban areas. In this study, over three-fourths (77%) of rural caregivers in the self-directed care group reported that the services received through the Self-Directed Care Program extended the time that they were able to provide care. These caregivers were significantly more likely to report this effect than rural POMP caregivers who received traditional agency-managed services. Findings from open-ended questions showed that financial support for supplies and access to respite were key protective factors.

The ability to hire friends, family members, and neighbors may have contributed to rural self-directed caregivers' increased overall satisfaction with services. Although no significant differences were found between the groups, more than half (52%) of rural self-directed caregivers reported that they preferred to hire someone they knew rather than someone from an agency, compared to 59% of urban self-directed caregivers who said they preferred to hire someone from an agency. These findings support previous research showing that rural caregivers prefer to receive assistance from informal helpers or manage care themselves (Morgan et al., 2002; Stoller, 1996). In rural communities, where reciprocity in relationships with friends and neighbors is paramount, asking for help can be especially stressful. Studies have shown that the ability to pay friends and neighbors for services can ease this stress and allow rural caregivers to maintain their value for self-reliance (Stoller, 1996; Shenk, 1998).

Results from this research also support previous research showing that caregivers in rural communities often experience significantly high levels of burden and stress (Dwyer et al., 1994). In this study, rural caregivers in the self-directed care group were more likely to live with the care receiver and provide a significantly higher proportion of care, compared to rural caregivers in the POMP group. These findings may help explain the higher burden rates among the rural caregivers in the self-directed care group. Caregiver burden is a risk factor for abuse and neglect, and contributes to overall lower quality of care (Dwyer et al., 1994). In addition to services provided through the Self-Directed Care Program, important protective factors identified in this study were caregivers' personal values for caregiving and their commitment to their caregiving role.

Consumer-Direction for Rural Communities: Current Status and Future Directions

This study contributes important information to the literature on consumer-directed care and has implications for future research. More research investigating the impact and effectiveness of consumer-direction in rural communities is needed.

Cost-effectiveness analysis should be an important component of this research. As this study shows, rural elders and their caregivers represent a diverse group. Georgia, for example, is one of seven southern states with a significantly high concentration of African American rural elders (Coward et al., 1998). Future research also should consider the effects of race.

To assist in policy, program, and service development, information learned from consumer-directed programs should be widely disseminated. Results from this evaluation have been presented at numerous state, regional, and national conferences and workshops. The findings also are included in a guidebook that has been distributed to AAAs and other government organizations nationwide and is available through the Division's website. Included in this guidebook are legal and financial guidelines and tips for training consumers compiled by a legal consultant who was contracted by the Division to provide technical assistance for the project. Feedback received from program planners in other states indicates that this information has been useful in planning new programs.

Finally, more funding is needed for consumer-directed care services in rural communities. When well designed, this model of care can be more cost-effective than expensive agency-based services or nursing home care. Barriers to the development and funding of these programs include federal and state regulations, resistance from provider organizations, and quality concerns (Infeld, 2004). Overcoming these obstacles will require organized advocacy at the national and state levels. Collecting comprehensive evaluation data on existing programs and expanding the current knowledge base through dissemination will be key to this effort.

Georgia aging services administrators and researchers have found the needs of older adults and their caregivers living in rural areas to be consistent in both research and practice. Families do need to have an awareness and understanding of available services. States should continue to expand consumer-directed programs in rural areas, given that rural caregivers have a reluctance to use formal services. Rural areas struggle with having enough funding, an adequate workforce, and the geographic distance between providers and consumers. Further, state allocation formulas should include a base allocation for assuredness of statewide provision of services and a weight factor for *rural* (land mass). Policy makers must acknowledge the distinctiveness of providing services to families living in rural areas through regional and state planning.

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Chapter 13
Rural Caregiving: A Quilt of Many Different Colors

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In this volume, we address the current status and future direction of rural caregiving in four areas: practice, education and training, research, and policy and advocacy. Several key themes in rural caregiving have emerged. These themes are presented and discussed in light of the personal, contextual, economic, environmental, and geographic characteristics that color rural caregiving.

Rural caregiving is described as a patchwork of often uncoordinated and scarce resources (Chwalisz, Buckwalter, & Talley, 2011) delivered through an amalgamation of *de facto* systems, thus refuting the "Mayberry myth" of rural cohesiveness and closeness as discussed by Morthland & Scogin (2011). Rural caregivers often manage to do a great deal with very few resources but, in contrast to their stereotype as "hale and hardy" (Buckwalter & Davis, 2011), they experience a variety of physical and mental health issues because of their caregiving efforts (Castro et al., 2007). Negative physical health affects are greater than those found among their urban peers (Gilliss, Davis, & Harper, 2011) and can be manifested by obesity (Elia, 2001), high blood pressure (Chobanian et al., 2003), diabetes (Meneilly & Tessier, 2001), and other chronic illnesses (Wolff et al., 2002). As noted by Morthland and Scogin (2011), negative mental health affects can be expressed in feelings of burden (Hannum Rose et al., 2007), loneliness (Stewart et al., 2006), depression (Lyons et al., 2007), anxiety (Teachman, 2006), anger (Gates et al., 2003), resentfulness (Schumacher et al., 2006), strain (Li et al., 2005), stress (Draper et al., 2007), mood disorders (Rosenberg et al., 2005), and cognitive disturbance (Garand et al., 2005). These effects are more pronounced among minority rural caregivers (Satcher, 2006).

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*The findings and conclusions in this chapter are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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Rural caregivers are generally older than urban caregivers and the primary caregivers in rural America are older women, who are also the most economically vulnerable and at risk (National Advisory Committee on Rural Health and Human Services, 2006). Compared with their urban peers, rural caregivers labor in a background of lower education, fewer local health-care resources, and less access to health care because of physical distance (Beverly et al., 2007; Campbell et al., 1998; Glasgow, 2000; International Longevity Center [ILC], 2006). Gilliss, Davis, & Harper (2011) note that rural caregivers not only provide care, but also coordinate the provision of care to their children *and* to elderly parents, essentially serving as case managers where elderly relatives are concerned. However, they receive more informal help from visiting relatives and community members, or fictive kin, than do small city or urban caregivers (Ray & Street, 2005). Relative kin, such as daughters or sons, might have out-migrated to urban areas and provide long-distance caregiving, often at great sacrifice, to supplement care provided by the primary on-site caregiver.

Rural caregivers are generally viewed as caring for the elderly, although this assumption ignores the life span nature of caregiving. Family caregivers, especially young families, must address the care needs of children and youth. For instance, in their chapter, Walker & Reschke (2011) note that someone other than parents spend time caring for 75% of the nation's infants and preschoolers. Further, families provide specialized care if they include a child or young adult with a chronic illness or disability (Murphy et al., 2007). Similarly, Buckwalter and Davis report that 87% of rural elders also need care for a chronic illness or disability. Thus, at both ends of the life span and everywhere in between, caregiving presents unique and complex challenges. These challenges are especially difficult for rural caregivers because of the factors discussed throughout this volume.

Current Status

Practice

The National Advisory Committee on Rural Health and Human Services (NACRHHS, 2006, 2007) has stated that fragmentation and lack of integration of services and funding streams are the primary barriers to providing rural caregivers with access to primary health, behavioral health, and social service care. Throughout this volume, we have reported on existing practices used to support rural caregivers. The findings suggest that, while often perceived as helpful, practices to support rural caregivers are generally disorganized, underfunded, unsustainable, directed to small groups of people, or lacking in data to support efficacy. Although there are exceptions to this picture, rural caregiving models have not yet met the NACRHHS standard of integrated funding, implementation, and evaluation. In this section, we review the current state of rural caregiving practices in three areas: structure and planning, interventions, and technology.

Structure and Planning

In their chapter, Buckwalter and Davis note that the health-care system does not provide adequate structures, whether formal or informal, to support rural caregivers. In some cases, home care serves as a substitute for other care options that are unavailable or inaccessible in rural areas. Because of the insufficiency of options and the general unavailability of nursing homes in rural areas (Rabig et al., 2006), home care is used at a higher rate by rural caregivers when compared with their urban counterparts. Many rural hospitals were built in the 1950s and do not have adequate facilities, technology, or adjunctive therapies, such as physical or occupational therapy, to support rural residents. Further, dental and emergency care services are often unavailable.

Greene, Perkins, Scott, & Burt (2011) note that in a state such as Georgia, where 56% of the land mass is rural and houses 33% of the older adult population, service delivery is a challenge. To a greater degree than urban areas, rural locations must address issues such as the limited number or unavailability of qualified service providers and the fact that these providers often must travel long distances between service locations. Thus, when considering the availability of quality nonrelative rural care providers, the dearth of well-trained, state-licensed employees becomes apparent. This shortage is most likely due to stress, burnout, low wages, geographic isolation, career advancement deficits, and lack of peer support among caregivers, and applies to both child and elder care.

Rural caregiving for children is typically defined by individual needs, family preferences, and care availability. As discussed by Walker & Reschke (2011), child-care arrangements in rural areas are found along continua of formality, structure, location, and provider; however, mothers still carry the primary responsibilities when making care decisions. The most frequently used form of non-parental child care is relative care and the most formal type is delivered in child-care centers. Inflexibility in formal care arrangements, care quality, and cost are major concerns for rural working parents. In their chapter, Walker and Reschke discuss startling findings from Schulman (2000), that a child's annual preschool costs in some rural areas can exceed the costs of a year of public college tuition. In regions that are already economically depressed, these costs constitute a major care barrier.

Wilken & Stanback (2011) note that one of the most advantageous strategies to employ when planning and initiating rural services is through coalition development. Coalitions bring membership from various community groups together with concerned volunteers and adhere to two of the fundamental tenets of successful rural services: local ownership and local planning. Coalitions are found at the national, regional or multistate, state, multi-county, single county, and community levels, and focus on various aspects of caregiving or caregiver populations.

Several models of caregiver coalitions have been implemented in the past decade (Elderberry Institute, 1999) and chronicled by the AARP (2003). National coalitions include the National Alliance for Caregiving, the ARCH Respite and Lifespan Coalitions, and the Relatives as Parents Program (Brookdale Foundation, n.d.). The Caregiver Assistance Network (found in southern Ohio and northern Kentucky) and Caring Community (a volunteer coalition based in Philadelphia, Pennsylvania) are multistate efforts. Examples of state-level coalitions are the Florida Kinship Support Group Network and California Coalition for Compassionate Care. Local coalitions are found in many sites throughout the country, including Flagstaff, Arizona (Community Caregiving Coalition of Greater Flagstaff) and Howard County, Maryland (north of Washington, D.C.)

One model of successful coalition building is found in the Georgia CARE-NETs (Dodd, 2004). Started by the Rosalynn Carter Institute for Caregiving (RCI) in 1990 in a multi-county area near Columbus, Georgia, the CARE-NET, or Caregivers Network, was conceived by Robert Newbrough, RCI Board member, and Jack Nottingham, RCI Executive Director, in Americus, Georgia, to address the needs of caregivers in that area. The model was expanded in 2002 with innovation grant funds from the National Family Caregivers Support Program (NFCSP) the first year the NFCSP was in effect. With the funds, the RCI, led by Jim Dodd and Terry Elder, expanded the model to encompass the entire state, ending the 3-year grant project with a total of 12 CARE-NETs throughout Georgia. The CARE-NET model also included one additional component recommended by Wilken and Stanback: a local champion, in this case, former First Lady Rosalynn Carter from Plains, Georgia.

Interventions

Successful interventions have a robust theoretical foundation, an appropriate balance of treatment amount and intensity, and a clear relationship between the treatment and desired outcomes. Treatment types are categorized in four domains: knowledge, skills, affect, and support (Chwalisz, Dollinger, Zerth, & Tamkin, 2011). They are research-based and comprehensive, addressing multiple caregiver needs, yet specifically relating to the caregiver's individual concerns.

Gilliss et al., emphasize that interventions for rural caregivers and care recipients must consider the family context of care, strengthen the family's capacity to positively address care needs, support adaptive family functioning, and emphasize health and well-being. Chwalisz, Dollinger et al., (2011) note that the majority of current interventions do not meet these standards, and focus on either caregiver education and training, or support. Interventions can be individual or group; preventive, supportive, or remedial; standardized or tailored; multicomponent or targeted; and delivered in-person or through telehealth technologies. Some caregiver interventions have also been atheoretical, providing an evaluation challenge, and have largely been conducted in urban settings, which undermines their generalizability to rural areas.

Prior to the authorization and appropriation of funds for the National Family Caregiver Support Program (NFCSP in 2001), interventions for caregivers were limited and secondary to the direct services provided to care receivers (Greene et al., 2011). Current interventions generally generate high consumer satisfaction, although they vary in effectiveness from moderate to low. An exception is the use of cognitive behavior therapy programs, which combat negative emotions and irrational beliefs that generate caregiver stress. The Medicaid Cash and Counseling intervention model, which began in 3 states and has been expanded to 12 more, is an example of a consumer-oriented program with positive, evidence-based outcomes (Cash and Counseling National Program Office, 2007). A large number of these states are rural ones in the south and midwest (Alabama, Arkansas, Florida, Illinois, Iowa, Kentucky, Minnesota, and West Virginia).

Nationally, much professional energy is being expended to document the evidence base of interventions and to disseminate this information to a broad audience. Because of the relative youth of the field of evidence-based caregiver programs, much past practice has focused on a "one-size-fits-all" approach, with little attention being given to documenting results. This scarcity of knowledge in evidence-based rural caregiver interventions has been addressed by several noted researchers, including Buckwalter and Chwalisz, two editors of this volume, as well as Scogin and Robinson, two contributors. In reporting on mental health needs in rural areas, Morthland and Scogin note the importance of mental health intervention delivery through in-home programs, which negates the need for transportation and the stigma that some individuals feel when seeking mental health services outside the home (Calico, 2011; Chwalisz, Dollinger et al., 2011).

An example of a practice-education model to benefit rural caregivers is found in the Arkansas Aging Initiative (Beverly et al., 2007). This effort, funded with Master Tobacco Settlement funds, was designed to assist older citizens. Started in 2001, the University of Arkansas Donald W. Reynolds Institute on Aging has established seven satellite centers across the state. The centers provide community education in partnership with local hospitals and also provide geriatric primary and specialty care.

Consumer-Directed Care

There is minimal research on consumer-directed care in rural communities. In a notable exception, the Georgia Division on Aging conducted 11 focus groups around the state to determine caregiver needs (Greene et al., 2011). The primary theme that emerged from the caregivers' discussions centered on compassion fatigue and frustration. Six experiential themes subsumed under this general heading were: (1) lack of information and coordination of resources; (2) needs exceeding availability; (3) ageist providers; (4) the lone caregiver (no one to help); (5) pushing against the tide (feeling that they were critically evaluated on the care they provided); and (6) living a dilemma (making decisions from among equally abhorrent options). To address these needs, the Division on Aging worked with the Area Agencies on Aging (AAA) to implement two care models: (1) mobile day care, which allows staff to travel in teams to deliver day care in rural community facilities, usually senior centers or religious institutions; and (2) consumer-directed care, which allows caregivers and care receivers to assess care needs, select resources to meet them, and evaluate care quality. The mobile day care model provides a means of sharing staff across agencies or counties, while consumer-directed care puts control in the hands of those affected, thus supporting self-reliance. These successful models have been replicated in other states.

Mental Health

Although theoretical models exist for understanding the mental health needs of rural caregivers (Human & Wasem, 1991), these models need to be empirically tested for relevance and adequacy among rural populations. Morthland and Scogin, noting that mental health effects are higher among rural caregiver samples than urban ones, recommend more research to inform best practices and policies. The research literature on rural caregivers' mental health needs should be enhanced with additional studies that consider the demographics of age, ethnicity, sex, and location. Research on the mental health of caregivers generally needs to be applied to rural populations in geographically diverse settings to ensure robustness.

In one study (Buckwalter & Davis, 2011), linking local Area Agencies on Aging with the mental health system was viewed as one of the most effective ways of providing mental health services to rural caregivers. Several other strategies exist for the provision of mental health services in rural areas. They include telehealth in best practices through HRSA's (Health Resources and Services Administration) Office for Advancement of Telehealth and the Telemedicine Information Exchange. The ALERTS (Alzheimer's Early Recognition Telephone System) intervention in Wisconsin provides telephone support to rural caregivers of individuals with Alzheimer disease and the Southern Illinois University Rural Caregiver Telehealth Intervention Trial offers it to rural caregivers of the elderly.

Technology

Advancing technological innovations provide an amazing array of new opportunities for records management; information sharing; intervention planning, implementation, and evaluation; communication; and research (Yellowlees et al., 2011). Because of the isolation and transportation challenges faced by rural caregivers and the difficulties providers have in reaching them, these strategies offer new hope for rural residents in need of hard-to-access medical care and support (Pew Internet & American Life Project, 2006).

Model Technology Adoption

One model of innovative technology use was initiated by the Care Coordination Program of the U.S. Department of Veterans Affairs (VA). The intervention provides intensive use of technology delivery strategies, such as telehealth, telementalhealth, and telesurgery (VA, 2007a). Store-and-forward technology, which allows patient health variables to be recorded at multiple times and periodically forwarded to providers, is currently employed by the Care Coordination Program to monitor ophthalmologic care among veterans with diabetes (VA, 2007b). Store-and-forward technology also has been used by other systems for dermatological wound care.

Education and Training

Both family and professional caregivers can benefit from targeted education on a variety of care issues. The number of education and training programs has increased dramatically over the past decade, in concert with the growing recognition of caregiver needs. However, as with other services, rural caregivers have difficulty benefitting from extant programs because of lack of access; unfamiliarity with the program or service providers; and unavailability of respite care, which would allow time away from the care recipient. In the case of mental health issues, perceived stigma might inhibit the caregiver's willingness to participate. In this section, we review the status of education and training programs for rural family and professional caregivers.

Family Caregivers

Chwalisz, Dollinger et al., note that to successfully navigate their roles, rural caregivers need knowledge in: (a) the changes they can expect in their caregiving roles, including transitions; (b) the care recipient's illness and potential treatments; (c) available services and community resources, as well as methods to increase their service network; and (d) relevant issues with which they might have to deal, including legal and financial concerns. Also, caregivers can benefit from education that increases their ability to employ a variety of skills, including care provision (e.g., behavior management), coping with stressful problems, communication (e.g., assertiveness training), and social problem solving (e.g., creativity and self-efficacy in solving difficulties). In the affective domain, caregivers need to develop skills in methods of stress management (e.g., relaxation training) and techniques for anger management (American Psychological Association, 2003a).

Although training programs for caregivers are abundant, as Chwalisz, Dollinger et al., note, few have been evaluated to determine their evidence base for desired outcomes. Provider-directed education materials are plentiful (Yellowlees et al., 2011), but as with interventions, randomized clinical trials and published research on their effectiveness is spotty. While steps are being made to remedy this situation (Anderson, 2007), much work remains.

There are some successful, evidence-based family caregiver programs that are discussed in depth by Chalwisz, Dollinger et al., and are a new area of emphasis for the Rosalynn Carter Institute for Caregiving. Other examples are offered by Yellowlees et al., who point to the benefits of using decision aids with family caregivers. For example, interactive software and Web applications have been found to reduce decisional conflict and indecision, two areas that contribute to caregiver burden. Professional guidelines for patient care decisions and best practices are available from professional caregivers who are trained in and deliver evidence-based practices. Rural communities are encouraged to prioritize local caregiver support needs, adopt research-based strategies to address these needs, and contribute to the emerging body of knowledge on evidence-based practice.

Professional Caregivers

In rural areas, there is a shortage of professional caregivers, such as physicians, nurses, psychologists, social workers, dentists, physical or occupational therapists, home-based service providers and first responders (e.g., emergency medical personnel and firefighters). Walker & Reschke (2011) also highlight the lack of state-credentialed preschool workers in rural child-care centers, whose numbers are diminishing as care workers either retire or move to locations perceived as more desirable.

In an effort to increase services in underserved areas, Congress has enacted legislation that allows education loan repayment for each year of service by professionals in the National Health Service Corps (NHSC) for work in Health Professions Shortages Areas (HPSA; Public Health Service Act as amended by Public Law 107–251, Healthcare Safety Net Amendments of 2002). Nearly 75% of the HPSA are rural settings. Of this number, 60% are also Mental Health Professions Shortage Areas (MHSA). Not only are there shortages of care providers, Calico notes that the Medicare program pays less to rural than to urban providers for the same service. Another legislative effort, the Quentin N. Burdick Program for Rural Interdisciplinary Training, which ran from 2000 through 2005, provided more than $41 million for interdisciplinary education and training to enrollees.

Most institutions that graduate professional caregivers (schools of medicine, nursing, allied health, etc.) are remiss in the translation of information about rural care and practice opportunities (Calico, 2011). While graduates need knowledge of and experience with service delivery in rural settings, this rarely occurs. Reasons for this oversight include the predominant location of training facilities in urban areas and the difficulty in accessing rural service areas. In a rural community health model, registered nurses (RNs) are found more often than other health-care providers and bear the burden of professional caregiving.

To frame the education and training needs of rural health professionals, *Quality Through Collaboration: The Future of Rural Health Care* (Committee for the Future of Rural Healthcare [CFRHC], Institute of Medicine [IOM], 2005) presented five skill needs to focus training programs: (1) provide patient-centered care, (2) collaborate through interdisciplinary teams, (3) implement evidence-based strategies, (4) apply quality improvement assurances, and (5) utilize informatics (see the application of these principles in *Future Directions: Education and Training, this chapter*).

There are some notable exceptions to the shortage of training programs that focus on rural practice. Two examples are the West Virginia University Rural Health Partnership Program, where health-care students have rural rotations, and the Jefferson Medical College of the Thomas Jefferson University Physician Shortage Area Program, which enrolls rural students in family practice who commit to service in a rural area after graduation. Both of these models are discussed by Calico in her chapter.

Despite these exemplary models, all too few health professions training programs offer a rural component. Internships in rural areas are similarly lacking. Most training programs do not offer content on geriatrics, cultural competency, self-care, or health literacy. Lastly, studies have yet to evaluate education over time and link patient outcomes to curriculum changes; of the available studies, most deal with physicians.

Some limited training is being made available to professional caregivers already in practice. Organizations such as the Direct Care Alliance have emerged as advocates for professional home caregivers and support critical training needs. In 2006, HHS promulgated new regulations to accelerate technology adoption by rural health-care providers. Under this provision, hospitals or other health-care entities can donate health technology and training services to health-care providers. With this service, professional caregivers will have financial assistance to implement health technology.

Research

Providing funds to researchers nationwide, the National Institutes of Health (NIH) awarded $169 million in 2003, $178 million in 2004, $199 million in 2005, $202 million in 2006, $207 million in 2007, and $170 million in 2008, $186 million in 2009, $207 million in 2010, $207 million (estimated) in 2011, and $211 million (estimated) in 2012 for research on rural health issues. While the NIH budget doubled during the period 1998 through 2003, the fiscal year 2006 HHS budget passed Congress and was signed into law with the first cuts to NIH in 36 years (American Association for the Advancement of Science [AAAS], 2005; NIH, 2007; Spotswood, 2006). As noted, funding for rural health research increased from 2003 through 2007, dropped precipitiously in 2008, increased slightly in 2009, and rose to the current approximate level for 2010–2012 (Table 13.1).

Despite federal research funding, current rural caregiving research is plagued by a variety of issues. Goins & Spencer (2011) note that current research on rural caregiving is characterized by overarching conceptual issues related to construct definitions and methodological research design. Although construct and methodological problems are present in any field of study, those inherent in rural caregiving research inhibit the ability to generalize from current data. For instance, the varying definitions of "rural" and "caregiver" make comparability across studies difficult. Indeed, the editors of this volume defined these terms in the introductory chapter to ensure consistency throughout this book. Goins & Spencer (2011) also debunk the myth that "rural caregivers take care of their own" and are "distrusting of outsiders," noting the lack of consensus on the definition of what constitutes "rural culture." Research that focuses on a distinct characteristic, such as rurality, must take a different approach to conducting meaningful research.

In terms of methodological issues, Goins & Spencer (2011) criticize an overreliance of self-report measures, which introduces bias, and single interval research, which provides a static view of the rural caregiving experience. Additionally, the majority of the research on rural caregiving has been conducted with small samples from racial or ethnic or disease-specific groups, or from geographic regions, including urban areas, thus limiting their generalizability. Relatedly, research on the rural health-care workforce has limited generalizability due to the use of varied research designs and methodologies (Calico, 2011).

Table 13.1 Evidence-based interventions for rural family caregivers

Researchers/providers	Intervention title	Intervention focus	Target population	Health focus	Service location	Results for family caregivers
Archbold and Associates (1995)	Preparedness, enrichment, predictability (PREP)	Interactionist and role theory model, addresses transitions and intervention timing	Caregivers of elders	MH PH	Home-based	Caregivers receive training from nurses in: 1. Systematic assessment and family focus 2. Local knowledge 3. Interventions using multiple strategies 4. Therapeutic relationships and transitions Caregivers reported: 1. Higher care effectiveness 2. Higher usefulness of in-home staff
Abraham et al. (1993)	Elderly Outreach Program (IO) the Abraham program was in Virginia,	Linked AAA resources w/ community mental health system providers	Elders and caregivers	MH	Home-based	• Effective service delivery to geographically and socially isolated areas • Cost-effective
Buckwalter et al. (1991); Smith and Buckwalter (1999)	Rural Elder Outreach Program (IA)					
Buckwalter and Davis (2002)	Relevance, Unity, Responsiveness, Access and Local Leadership (R.U.R.A.L.)	In-home assessment and intervention				

Buckwalter et al. (1992)	Progressively Lowered Stress Threshold (PLST)	Education and behavior management skills	Dementia caregivers	MH	Home-based	1. Felt better about their situation 2. Had more satisfaction w/ cg. experience 3. Increased sense of mastery 4. Decreased burden, uncertainty, depression
Chwalisz and Dollinger (2002); Chwalisz (2003)	SIU Rural Caregiver Telehealth Intervention Trial (IL)	Information, resources, services, strategies, problem-solving, managing behavior and connection tips	Elder caregivers	MH	Telephone-based system	
Elder Services, Inc., Iowa City, IA	Family Caregiver Support Program	Information, assistance, and family cg. counseling	Elders and caregivers	MH	Home-based	Information/Assistance Specialist provides: 1. Counseling 2. Mediation 3. Education in cg. skills 4. Coordination w/community services/resources
Foster et al. (2005)	Demonstration project (AK)	Tailored interventions	Caregivers and frail elders	MH PH	Home or services group	Results: Caregivers who were allowed to select/direct service delivery: 1. Required less assistance 2. Reported greater emotional, physical, and economic well-being

(continued)

Table 13.1 (continued)

Researchers/providers	Intervention title	Intervention focus	Target population	Health focus	Service location	Results for family caregivers
Greene et al. (2007)	Consumer-directed Care	Consumer assessment, service and provider selection, evaluation	Rural elderly caregivers and care recipients	PH MH	Generally home-based (consumer choice)	1. Safe, cost-effective way to allocate limited resources and deliver care 2. Client satisfaction and service quality more highly rated than agency-based care 3. Services made it possible for cg. to care for a longer period of time
Greene et al. (2007)	Mobile day care	Respite for caregiver; stimulation and nutrition for care recipients	Rural elderly caregivers and care recipients	PH MH	Staff mobile, service in community facility	1. Service provision in previously unserved areas 4. Maintains consumer at home 5. Cost-effective alternative to nursing home placement 6. Respite for caregiver 7. Increased staff retention due to flexibility with part- and full-time positions
Mittelman et al. (1993)		Tailored interventions in 4 areas (see far right column)	AD cgs. and families	MH PH		Caregivers received interventions addressing: 1. Cg. and family communication skills 2. Primary caregiver support 3. Family conflict management 4. Dementia home-care skills Results: Education, support, respite interventions were beneficial for caregivers and families

Robinson et al. (2003)	Volunteer Caregivers Program (VCP) (KY)	Faith-based, volunteers provide in-home respite	Dementia caregivers	MH PH	Home- and community-based	Additional free services: 1. Assessment and care planning 2. Education, information, and referral 3. Evaluation and support groups 4. Community-wide services: a. Memory screening b. Community education programs
Scogin et al. (2004)	Project to Enhance Aged Rural Living (PEARL)	Cognitive-behavioral therapy	Elders and caregivers	MH	Home-based	Caregivers taught: 1. Techniques to facilitate elder therapy 2. Strategies to improve their own lives Results for caregivers: 1. Higher perceived QoL 2. Lower level of psychological distress
Schulz et al. (2003)	Resources to Enhance Alzheimer's Caregiver Health (REACH)	Tailored interventions based on identified needs	AD cgs. and families from diverse social, geographic, and ethnic backgrounds	MH PH		Caregivers received interventions addressing: 1. Telephone/computer-based counseling and support 2. Group and family therapies 3. Psychoeducational training 4. Home-based environmental adaptations

(continued)

Table 13.1 (continued)

Researchers/providers	Intervention title	Intervention focus	Target population	Health focus	Service location	Results for family caregivers
Strozier et al. (2004)	Kinship Care Connection	Education and psycho-social intervention strategies	Grandparents raising grandchildren	MH PH	School-based	Grandparent: Mediated kin care burden Grandchildren: Increased self-esteem
	Alzheimer's Early Recognition Telephone System (ALERTS) (WI)	Information on AD/dementias, screening, resources	Alzheimer caregivers	MH	Free telephone-based system	1. Cg. assessment tool to monitor stress and depression 2. Information on care strategies, tips on addressing common challenges, what to expect with disease progression, and importance of self-care

PH, physical health; *MH*, mental health

Note: Additional information on evidence-based interventions may be found at www.rosalynncarter.org (2011)

In their paper, Chwalisz, Dollinger et al. (2011) note that caregiver interventions include the domains of knowledge, skills, affect, and support. These domains have empirical support. However, intervention components in these areas have not received sufficient evaluation, either individually or comprehensively. Many intervention studies lack external validity or generalizability because of their narrow focus; do not use a population-based approach; and exclude subpopulations of the elderly, such as minorities, intergenerational caregivers, and caregivers with specific illnesses. Further, documentation of post-intervention outcomes has been elusive because of the insensitivity of the variables measured. Caregivers often report that they benefit from the process of providing care. Recently, researchers have been focusing on the reported rewards of caregiving. Documented benefits include improved self-efficacy, enhanced self-respect, and perceived meaning by caregivers of their role.

In summary, "conventional research has a contentious history and offers limited opportunities to improve the health and well-being of the people in [rural] communities" (Goins & Spencer, 2011). Fortunately, new opportunities to address these deficits are emerging on the rural landscape.

Policy and Advocacy

National, state, and local policies all have an effect on the delivery of assistance to rural family caregivers. Policy provides the underpinnings to legislation and appropriation, which, in turn, drives behavior and change. Currently, rural caregivers have benefitted incrementally from extant legislation. Rural caregiving is an underdeveloped national issue; however, the potential for change based upon effective advocacy and research is great. Given the current state of American caregiving policy, there is much room for growth.

At almost every level – federal, state, and local – research, policy, legislation, and appropriations are needed to support rural caregivers. As the foundation of policy, research serves an important function: informing the issue. Policy, if compelling and supported by vocal advocates, can be translated into legislative language, which will (hopefully) result in a bill that is passed through the necessary chambers and signed by the president, governor, mayor, or other official leading the vicinity's government. Advocacy organizations, associations, and groups with governmental sanction provide input into policy development at all levels.

While U.S. legislation and policy to support caregivers lags behind efforts in some countries (e.g., England, Australia, and France), there are two important federal legislative initiatives that have received much attention. First, the National Family Caregiver Support Program (NFCSP) of the Older American's Act Amendments (P.L. 106–501; 2000) was the first of its kind caregiver legislation. Under NFCSP, funds and technical assistance were provided to Area Agencies on Aging (AAAs) to implement a variety of caregiver interventions for the elderly and for some parents caring for a disabled child. After passage of this landmark legislation as part of the Older Americans Act Amendments of 2000, advances in all facets of caregiver assistance have exploded. Maintaining and expanding funding for the NFCSP is a priority with all national caregiver organizations and is a key advocacy area.

The second major piece of legislation deserving attention is the Lifespan Respite Care Act of 2006 (P.L. 109–442), which was signed into law on December 21, 2006. After many years of concerted advocacy by the Lifespan Respite Task Force, a coalition of 170 organizations, this legislation authorized $289 million over 5 years for state life span respite programs. The purpose of the act is to provide families with affordable, quality respite care, which is defined in the act as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult” (P.L. 109–442, p. 2).

Technology is also an advocacy concern for rural caregivers. As noted earlier, many elderly rural caregivers lack sufficient access to existing technologies or knowledge of their use. In 2005, as an effort to begin addressing these issues, the secretary of HHS created a council, the American Health Information Community (AHIC) charged with accelerating technology adoption. The AHIC’s work led to the establishment of an alliance that is collaborating to address challenges in providing an interoperable health information exchange (HIE) within and across states. The development of a Nationwide Health Information Network (NHIN; HHS, 2007a) can contribute to rural caregiver health by providing a nationwide HIE that connects professional caregivers and family caregivers in a variety of creative permutations.

Future Directions

In the previous section, we outlined themes in current rural caregiving practice, education and training, research, and policy and advocacy. As noted, many advances in these areas have occurred. However, as our authors have highlighted, much remains to be accomplished to ensure that services to support rural caregivers are of high quality, comprehensive, integrated, and accessible. The following sections provide guidance and potential solutions to these challenges.

Practice

A population-based public health approach of combating both physical and mental illness has a history of acceptance in rural areas. Population-focused models promote the community’s health by integrating primary care with public health. A primary-care and public health model can offer culturally sensitive behavioral health and other integrated services that lead to increased access and better outcomes for rural residents. For instance, within an integrated model that has less separation of infrastructure, providers, and services than many current models, there may be increased: (a) information sharing among providers, care recipients, and caregivers; (b) avoidance of service gaps, contraindicated services, or incompatible medications from different providers; and (c) coordination of needed services with available resources. Further, a service integration model that offers family-centered, wrap-around services encourages a holistic approach to illness prevention and health promotion (Bolda & Seavey, 2000).

Community groups, such as places of worship, schools, and senior centers, might choose to offer caregiver programs for health promotion, disease prevention, and symptom management. Also, the groups might make interventions available through telehealth technologies. However, there is some evidence that available services are currently being underused because of a lack of recognition of the "caregiver" role that caregivers assume (Chwalisz et al., 2011). To address this issue, we must not only increase caregiver access, but also address the issue of caregivers not accessing available services.

Interventions

Rural populations need interventions specifically designed for rural areas. Interventions for caregivers should be available pre-caregiving and targeted to populations who are at high risk for becoming caregivers (e.g., spouses, daughters, and daughters-in-law). Interventions should also be available at the first signs of an individual's need for them, long before institutionalization of the care recipient, and should continue post-death to assist the caregiver with issues surrounding grief, loss, and mourning.

Practice interventions for parents of young children should be crafted to meet their care needs as well as those of preschool care providers. Further, Head Start and Early Head Start programs for preschool children in rural areas should be made increasingly available. By offering these programs, trained preschool personnel provide services that might be the only ones available for young children in the area, while addressing developmental child-care needs (NACRHHS, 2006). For adult caregivers of their children (who might also be adults) with intellectual or physical disabilities, strategies are needed in preparation for the time when the parents are no longer able to provide such care.

Importantly, because caregivers are more likely to carry out a care plan if they are involved in creating it, rural caregivers and their care recipients should be part of the care planning team. Services for caregivers and care recipients must be designed by them. They should be *encouraged* to participate in both the planning and the implementation processes. Strategy planning and implementation must be respectful of family choices and preferences, taking into consideration the increasingly older caregiver and care-recipient populations whose learning styles and needs might differ from those of their children or grandchildren (Wilken & Stanback, 2011).

Interventions should engage family members as a caregiving unit, assist them in developing dynamic family caregiving plans, and provide guidance for the inevitable family caregiving conflicts (Gilliss et al., 2011). Services must be provided while maintaining the dignity, privacy, and autonomy of the caregiver(s) and the care recipient(s). Because multicomponent caregiver interventions are more effective than single-component interventions (Gilliss et al., 2011), future interventions should be multicomponent and address aging and chronic disease education, caregiver and family counseling, respite services, and support to enhance family functioning.

Care Systems

Community services must be planned by representatives from the areas in which they will be implemented, thus promoting pride of ownership. Services should be coordinated; to that end, local departments of mental health and public health, as well as local school boards, should collaborate to plan, fund, implement, and evaluate rural interventions. Importantly, blended funding streams across agencies should be used to maximize services and eliminate service gaps. The public health system should provide assurance to the public that the needs of rural caregivers are being appropriately addressed in state and local public health plans. Further, because access to services is a major issue, especially for ethnic and racial minorities, Greer (2011) recommends developing rural partnerships among health-care administrators, transit operators, and other community leaders for the sole purpose of assessing community transit needs and developing strategic plans to improve transit access. Indeed, the provision of transportation and respite care are important considerations when planning face-to-face caregiver activities, such as support groups.

Chwalisz et al. (2011) note that rural services need better coordination; Calico (2011) suggests that the timely provision of primary care must be a community priority. Professional caregivers working in rural areas must promote the health and well-being of rural Americans while they also provide treatment for their patients' immediate health concerns. One means of addressing these concerns might be found in multiple provider practices, which share care provision across providers, thus reducing each participating provider's workload and burden of care. Another option is promoted by Gilliss (2011), who recommends developing care partnership systems of family and community members who work together to provide needed services. A third option would be for rural health-care staff to seek collaborations with health-care specialists in adjacent or neighboring urban communities (Greer, 2011).

However, it is difficult for rural America to make such changes when there is a dearth of professional caregivers in those areas. The shortage has led to: (a) generalists taking on the roles of specialists, (b) mid-level health professionals assuming delivery of local health care; (c) paraprofessionals trying to perform high-level tasks for which they are untrained; and (d) family caregivers assuming the role of medical technician, duties which make some uncomfortable because they represent tasks for which they were not trained (Wilkin & Stanback, 2011). In order to address these issues and attract health care professionals, especially specialists, rural health care administrators and policy makers must offer practice incentives. These should include financial changes such as: (a) innovative reimbursement structures to reward quality and allow payment for the time professional caregivers spend with family caregivers; (b) incentivization of integrated service delivery models; (c) formulas for providing cutting-edge technological equipment and training to caregivers, including place-based education; (d) repayment of education loans by the federal government, expanding HPSA and MHSA; (e) bonuses for professional caregivers who agree to provide rural services; and (f) service tax credits.

Pipeline strategies in which elementary, middle, high school, and college students who are exposed to and have experience with rural caregivers might prove useful in grooming future providers (see *Future Directions in Policy/Advocacy* later in the chapter for translation of this practice recommendation into proposed legislation). By offering students an education in science and other health-related subjects, the community might increase student interest in health care careers than non-residents. This strategy holds great promise because recruits from local areas are more willing to remain there to practice, understand the local cultural and ethnic norms, and have proficiency in the prevailing language.

Mental Health

To address the mental health effects of caregiving, rural intervention programs need to be well-managed, coordinated, permanent components of the greater rural healthcare delivery system (Morthland & Scogin, 2011). Specialized mental health practices and interventions must be developed for rural caregivers, with a focus on providing services in an environment that is comfortable to the caregiver. Interventions delivered in the home through visitation or through a telehealth network, or in the community, are growing in number (Buckwalter & Davis; Chwalisz, Dollinger et al.; Morthland & Scogin). The public health system might be a resource, particularly in an integrated service delivery model.

Future mental health interventions should be based on empirically valid studies of efficacy, taking into account the unique features of rural caregivers and communities. Communities must be sensitive to individual caregivers and their mental health needs. Because negative feelings are sometimes aroused during caregiving and can affect the caregiving process, emotional concerns should be addressed with family caregivers when meeting with them (either in person or through other media). Family caregivers must receive assurance from providers that mental health challenges are often part of the caregiving experience. Further, efforts are needed to ensure that no stigma is attached to mental health service use (APA, 2003b).

Technology

Telehealth services must be integrated into rural caregiver practice and both professional and family caregivers must be trained in their use (Morthland & Scogin, 2011). To accomplish this goal, telehealth connections and equipment must evolve in pace with technological innovation. This includes infrastructure development using both wired and wireless facilities.

Innovative intervention delivery must be employed for future rural practice and include new uses for standard equipment, such as telephone-based services, as well as new and emerging technologies, such as videophone skill training, multimedia electronic mail (e-mail), interactive two-way computer connections, wireless networking, and geographical information systems (GIS). Yellowlees et al. (2011) highlight the usefulness of these strategies for sharing electronic medical records and information retrieval, which allows for remote monitoring of patient and caregiver health; interpretation of language and cultural nuances; decision support for professional caregivers; and telesurgery, through either direct robotic surgery or consultation with surgeons as they operate.

We anticipate that there will be considerable expansion in remote consultations for both inpatient and outpatient services, such as consultations with specialists and emergency medical personnel. Examples are the connection of pediatricians with hospital emergency room personnel when caring for ill or injured children or linking cancer specialists to providers of care for individuals with rare forms of the disease. Pharmacological consultation via technology will provide the means by which remote pharmacists can review and coordinate medications for hospitals without 24-h pharmacy services. With these changes, accreditation standards for telemedicine will evolve to protect consumers, likely becoming more stringent. Shared patient-caregiver-provider electronic records will provide access to all critical parties and serve as an additional communication tool for all patients to chronicle and update one another. GIS systems will be used to determine the accessibility of a site where services are needed. GIS will be used in research for data collection on caregiver behavior patterns and service use. Ultimately, GIS will be useful in determining future service delivery locations (Wilken & Stanback, 2011), where convenience is a major factor in use.

In terms of Internet technology, Yellowlees et al. (2011) note several important ways that it can be helpful to rural caregivers. First, it can serve to provide prescriptive or self-directed disease education. Second, communication and support is available through Internet groups, including chat rooms. Third, person-to-person e-mail can serve to connect caregivers and care recipients with others in their same situations and with care providers. The Internet serves as a vehicle for many forms of home telemedicine, such as telementalhealth and telesurgery, as well as the telemonitoring of cardiac conditions, wounds, weight, blood sugar, blood pressure, and pulse, to name just a few. Further, the Internet or e-mail services also might be one means of providing confidential services while avoiding illness stigma, particularly in the case of mental illness (see *Caregiving and Mental Health,* this series). As websites evolve to offer user recognition, intelligent search engines will assist consumers in finding needed information.

As young cohorts age, we can expect to see the Internet as an increasingly important source of information for people of all ages. This is important for the elderly, particularly those in rural areas, because their relative isolation and health challenges make information access difficult. E-health technologies, including the Internet, will make education, diagnosis, and some forms of service delivery increasingly available.

Online groups offer another support option for rural family caregivers. While rural areas might have only one or two caregivers of individuals with a particular disease, electronic support groups can connect many rural caregivers and provide access to support that would otherwise be unavailable. Also, employers might offer online support groups as part of their "caregiver wellness" benefits. One example is the 3M Company, at which employees have access to daily online support groups. The company states that participants rate interactive options most favorably among a variety of available caregiver support options.

Because the availability of television makes it a prime source of information for people of all ages and geographic locations, this medium should be explored further for its utility in providing accurate information and targeted support to caregivers and care receivers (see Nussbaum and Fisher, *Intergenerational Caregiving,* this series). Broadcasts of data-based and dramatic programs, through both the Internet and television, have the potential to provide information to rural caregivers and care recipients (Horrigan, 2006).

Our recommendations to improve practice in rural caregiving concur with those identified by the IOM's CFRHC (2005; as reported by Chwalisz, Dollinger et al.). The committee has delineated community action needs for rural care provision that include: (a) an integrated approach to personal and population health; (b) a strong support structure to enhance quality health care delivery; (c) a prepared and sufficient workforce to ensure access to health care; (d) empowered caregivers to participate in intervention planning and evaluation; (e) a financially stable health-care system; and (f) an investment in communications and information technology.

With the integration of technological, organizational, and human factors, technology is both successful and sustainable. The increasing emergence of telehealth, including telementalhealth and telepharmacy, holds promise for dramatically changing the landscape of quality medical provision in rural America.

Education and Training

Family Caregivers

Gilliss et al. (2011) note that successful caregiving families have three characteristics: (1) good problem-solving skills; (2) good communication skills, particularly during stressful times; and (3) sound decision-making skills. Rural caregivers of elderly individuals need these and other skills, including the ability to (a) monitor and interpret symptoms of illness, (b) manage medication schedules, (c) offer direct care, (d) locate and access resources, (e) provide affective support, and (f) make sound decisions. To facilitate acquisition of these skills, more consumer education and better referral services should be provided (Buckwalter & Davis, 2011). Intervention training must enhance the caregiver's ability to seek out and find assistance from their social networks (Chwalisz, Dollinger et al., 2011). Research-based knowledge must be used to inform caregiver education and training, to assist communities, and to advocate with policy makers (Buckwalter & Davis).

As noted by Walker & Resche (2011) education for rural caregivers must empower them, building on tenets of support, respect, and connectivity. To address this goal, exploration into innovative means of implementing educational programs in rural areas should be encouraged. Innovative strategies must build on existing distance learning and other technologies to provide information, instruction, and connectivity to caregivers without consideration of distance or transportation difficulty.

With the increasing diversity in rural area, it is important to train both professional and family caregivers in racial, cultural, and ethnic issues. Hispanic populations are projected to become the largest minority group in the country and Latinos are increasingly moving to rural America. Hispanics and Latinos as well as African-Americans and American-Indians are all underrepresented in the professional caregiver workforce. To keep people from these and other minority racial and ethnic groups from becoming disenfranchised from their own communities and to increase minority representation in the health-care workforce, communities must provide culturally appropriate recruitment, counseling, educational opportunities, and support to its minority members.

We recommend that rural communities interested in improving education and training programs begin the process by seeking information about programs and initiatives that have been successfully implemented in other rural locations. These data can then be used to determine if the implementation of similar programs will meet the needs of communities that have been targeted for change.

Professional Caregivers

Education of health professionals should prepare graduates to address the complex needs of a rural clientele, especially their need for care coordination for those who are older or have disabilities, and the complexities of family care dynamics. A population-based orientation that concentrates on interdisciplinary, evidence-based care must be taught to health-care providers at their first medical education setting and continued throughout their career. Training in cultural competence, including recognizing biased behaviors by health-care providers and improving communication skills, especially with individuals whose first language is not English, is needed. To facilitate this goal, culturally sensitive curricula must be developed (Wilken & Stanback, 2011). Special attention must be paid to the recruitment of minorities into the health-care professions (National Rural Health Association [NRHA], 2006).

As part of their regular medical education, primary-care physicians and internists should have rotations that prepare them for the delivery of services, including mental health interventions, in rural areas. In addition, rural and family health care, as well as informatics and patient-centered care content, should be included in the curricula of health professionals. To facilitate learning, lectures should be replaced by interactive modes of instruction that employ rural, problem-based interdisciplinary case studies (Calico, 2011).

Primary-care physicians who are already practicing in rural communities should develop skills in screening for mental health problems and make it an integral part of their routine care; they also need the information to make appropriate referrals

(Porche & Margolis, 2006). Mental health service providers, such as physicians, psychologists, social workers, nurses, and clergy, need to be trained in cutting-edge interventions that are culturally and ethnically sensitive. Ongoing diversity training for currently practicing rural professionals is needed to prepare them for cross-cultural as well as intracultural interactions (Greer, 2011).

Efforts should be made to boost the supply of health professionals in rural areas (CFRHC, 2005). Recruitment strategies at every point along the rural workforce pipeline are needed. These include: (1) enhanced preparation of rural elementary and high school students to pursue health careers; (2) stronger commitment of health profession education programs to recruiting students from rural areas, educating and training students in rural areas, and adopting rural-appropriate curricula; and (3) stronger incentives for health professionals to seek and retain employment in rural areas.

One example of the kind of out-of-the-box thinking that is needed to address the anticipated personnel shortage in rural areas is the International Longevity Center's (ILC) grant program for community colleges (ILC, 2007). Funded by the MetLife Foundation, the program awarded 12 grants to local community or technical colleges to develop curricula for use with family and professional caregivers, such as home health or nurse's aides, to provide home-based care to older individuals. Programs such as this provide examples of innovative strategies to meet the critical need for the recruitment of new rural service providers, as well as the replacement of personnel who are retiring.

Technology

Preparation for the introduction of technology is key to its success in education and intervention. Moving from concept to application, technology training must be offered at a pace that is comfortable to the family caregiver and allow frequent "booster" sessions to maintain proficiency. Increasingly, highly focused, electronic educational materials, which are prescribed as part of a treatment plan, will be found on the Internet or distributed on compact disks. Other new technologies in virtual reality, such as motion sensing, immersive displays, and augmented reality, will provide simulations that depict effective modeling for family caregivers and patients undergoing significant procedures. Further modeling could allow patients and caregivers to select different scenarios or options for virtual medical care, which may assist them with their real-life medical choices.

Research

Throughout this volume, authors have indicated a variety of research needs in rural caregiving. While there are rural research barriers, such as distance and diversity, as well as lack of funding, researchers, and adequate sample sizes, contributors to this volume suggest a number of creative approaches to these dilemmas. In the next section, these issues are explored and recommendations are made to assist rural caregiving researchers in developing their research plans.

Definitions

In terms of definitional issues, Goins & Spencer (2011) point to the need for consistent operational definitions of several key terms. For example, "rural," "rural area," and "rural culture" are inconsistently used in the literature, thus inhibiting cross-study comparisons. Use of specific definitions could be promoted if journal editorial staff required them as a condition for publication. Longitudinal studies using multiple measures, which are discussed in the next section, are another means to achieve this goal. The "diversity" of rural caregiving and the "strategies" currently used to support caregivers must be more clearly defined in future caregiving research.

Paradigms

The majority of rural caregiving research to date has targeted small samples and usually has been connected to a specific geographic region. These limitations have produced very few comparable data on rural communities and consumers, as well as on rural and urban areas. If rural caregiving research is to be generalizable, probability samples rather than purposive or convenience samples are needed and methodological, as well as design, issues must be addressed.

To obviate these constraints, Goins and Spencer suggest the use of both qualitative and quantitative research in rural caregiving to provide a comprehensive picture of the needs, abilities, resources, and supports that exist in that context as well as to increase the reliability and validity of research results. For instance, the qualitative observation and recording of behavior as well as ratings may improve treatment fidelity. They suggest that longitudinal studies using multiple methods, including both etic and emic designs, provide a more useful dataset on which to base intervention designs than extant ones. While researchers often use self-report as a means of data collection, Goins & Spencer (2011) suggest that more objective measures, such as physiological factors, be used in future research. Program evaluation is also critical (Wilken & Stanback, 2011), for example, in determining the results of programs supporting grandparents raising grandchildren.

Community-based participatory approaches might be constructive. These require involved parties to: (a) recognize the identity of each community and build on its strengths and resources; (b) facilitate cooperative and collaborative relationships at all phases of the research; (c) integrate knowledge and action to empower and benefit all partners; (d) address physical and mental health issues from a positive, ecological perspective; and (d) disseminate research findings to all relevant individuals and groups. Within this paradigm, the team engages in a cyclical and iterative process.

Research paradigms based on family theory are essential to address the combinations of care that are most effective. Gilliss et al. stress that research designs should extend intervention testing to address both caregivers and care recipients, including their physical and mental health outcomes. For instance, with increasing rates of long-distance caregiving of rural individuals, what combination of on-site primary caregiver, long-distance caregiver, relative kin, and fictive kin is most effective in light of a particular profile of care recipient needs and cultural sensitivities? Also, how do we document longitudinal care transitions and challenges?

Interventions

The magnitude of unmet need and the adequacy of current care provision in rural American are unknown. We know little about caregiver knowledge of legal and financial processes as well as their level of competence in chronic illness care and self-managed pain. While we infer that rural residence influences the caregiving experience, we need clarification of the factors that have the most effect. Research on service use patterns and psychological barriers to service is sparse (Chwalisz, Dollinger et al.); however, research has shown that rural caregivers are less likely than their urban counterpoints to utilize formal support services (Easter Seals & NAC, 2006).

Many caregiver interventions have a deficient or nonexistent research base. While we expect them to be theoretically supported and evaluated, empirical testing is lacking on many interventions. A stronger evidence base is needed on the processes and outcomes of rural care. For instance, we need research that compares targeted interventions on multicomponent ones (Chwalisz, Dollinger et al.) and tailored and tailored interventions to general ones. Other studies might deal with threshold issues, for example, how much intervention or what combination of interventions is needed to yield positive outcomes with specific types of caregivers? Are different interventions needed at different points in the caregiver's career? What are the characteristics of transitions between home and long-term care environments, as well as rural to resource-rich urban areas? Are peer interventions more effective than those provided by non-peer relatives or professional caregivers? What facets of peer interventions might make them effective and in what circumstances? How do training models differentially affect intervention effectiveness? What are successful interventions to address caregivers' public health concerns, such as disease prevention and health promotion? For rural caregivers with mental or behaviorial health needs, what interventions provided by psychologists, counselors, social workers, and other mental health service providers are most efficacious?

Inquiry Topics

The effect of rural caregiving on physical, mental, social and economic outcomes deserves attention. Our research agenda should include caregiver safety and injury prevention, as well as family interests, and address the effect of various care settings on the development of children, youth, and people with disabilities and chronic illnesses. Additional research could focus on how families operate to provide care and how variations in care provision affects desired outcomes.

Morthland & Scogin (2011) suggest research on the mental health effects of caregiving using *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) (American Psychiatric Association, 2000) criteria, which focus on causal factors. Another classification system to consider when designing research is the *International Classification of Functioning, Disability and Health* (ICF) (2001) of the World Health Organization, which emphasizes effect. If using DSM-IV-TR criteria, outcome variables might include sleep disorders, depression, anxiety, burden, and stress. If using IFC criteria, questions could focus on: (a) body functions (e.g., mental or sensory), (b) body structures (e.g., immunological and respiratory systems and movement structures), (c) activities and participation (e.g., learning and applying knowledge and self-care), and (d) environmental factors (e.g., attitudes, support, and relationships).

Research is needed on a variety of other rural caregiving issues. These include coping strategies that mediate the stressors, strains, intrapsychic factors, and mood or cognitive disturbances experienced by rural caregivers; the cultural relevance of current measures of mental health effects for minority rural caregivers; service-volume outcomes; evidence-based retention strategies; and the benefits of forming care collaboratives or coalitions, such as the CARE-NET model mentioned earlier.

Strategies

In implementing any research project, communication is a key concern. To minimize miscommunication with rural residents on the goals and outcomes of a research project, Goins and Spencer recommend identifying local community members and organizations, or a community gatekeeper, to help legitimize the effort and possibly serve as project representatives or sponsors. As suggested by Wilken & Stanback (2011), research methodologies and techniques must be sensitive to rural respondents and their time. As such, questions might be asked in home settings via face-to-face interview, or by telephone.

Culture/Race

Future rural caregiving research must also embrace race and cultural diversity. While research on the effect of race or ethnicity is often centered in urban areas, rural America is becoming increasingly diverse because of the inmigration of city workers who wish to retire to rural settings and foreign-born farm and factory workers. Caregiving research on the effects of residential longevity, economic status, support networks, and care patterns for both children and adults could provide much-needed intervention planning information.

Workforce

Projections indicate that the direct care workforce will increase by 7% while the need for direct care workers will rise 104% from 2000 until 2030 (Paraprofessional Healthcare Institute [PHI], n.d.). While many rural states have not yet established plans to meet future care needs, Montana is an example of one that has taken steps to address this critical shortage. Beginning in January 2009, the state will provide increased Medicare payments to agencies that provide in-home care so that they can purchase health-care insurance for personal care attendants and private duty nurses (PHI, 2007). There is a paucity of research on the geriatric rural health-care workforce and settings, yet we know that a high number of older adults reside in rural communities and would most likely yield a significant benefit from the Montana strategy, which is designed to keep in-home care personnel in the workforce.

There is inadequate research on practice patterns of various care providers, such as occupational therapists and clergy, as well as insufficient replication of care studies over time (Calico, 2011). Further, data are needed on the efficacy of rural geriatric training models, staffing patterns, and quality care. We must know, for example, what components of professional caregiver training in urban settings successfully translates to rural practice. While planning to meet rural in-home care needs, we must evaluate and create strategies to increase rural dentistry, pharmacy, and related services, as well as emergency medical services.

Technology

Regardless of its name – telehealth, telementalhealth, telesurgery, telemonitoring, or e-health, e-mental health – the use of technology to reach individuals in remote locations has taken hold. To monitor the use of emerging technology in rural areas, Yellowlees et al. (2011) call for large, randomized controlled trials in telehome care to bolster the case for adoption of the technological innovations, such as two-way videoconferencing.

Further, research is needed on electronic appointments and patient records. While few systems allow patients or caregivers to set their own appointments in real time, this is a trend for future practice and both positive and negative outcomes must be documented. The sharing of patient records in electronic format, while safeguarding privacy and confidentiality, is an emerging practice that must be evaluated to determine intended and unintended consequences, as well as cost-effectiveness. Chwalisz, Dollinger et al. (2011) join Yellowlees et al. (2011) in a call for more research that compares various telehealth interventions with traditional services, including cost–benefit analyses.

Policy and Advocacy

Currently, many policy makers know little about the gaps in rural health service delivery and the plight of the rural caregiver who is often the sole support for his or her care recipient. However, the political landscape is changing as more legislators are called on to address the personal caregiving needs of their aging parents and their own health-care needs as they age. As policy is made, our leaders must have a sense of the distinctiveness of rural caregiving and of the needs of those who provide care. Advocacy for rural caregiving must focus on assisting legislators to recognize caregiving for the important issue it is, and rural caregiving as a complex set of unique challenges. In one effort to educate federal legislators on these issues, in May 2007, the National Rural Health Association launched an e-newsletter, *Amber Waves*, to inform Capitol Hill staff on rural health issues (NRHA, 2007).

National organizations (e.g., the National Family Caregivers Association and the National Center on Caregiving) draw attention to the needs of caregivers and provide representation before legislators. For instance, in their *2007 National Policy Statement*, the Family Caregiver Alliance (FCA) championed eight policy objectives that would greatly benefit all caregivers, including those in rural areas: (1) provide adequate funding for programs that assist family caregivers; (2) expand caregiver support services for family members of wounded Armed Forces personnel and veterans; (3) enact legislation providing refundable tax credits for family caregivers and employers; (4) strengthen Social Security by recognizing the work of family caregivers; (5) modernize Medicare and Medicaid to better support family caregivers; (6) expand the Family and Medical Leave Act; (7) commission an IOM study on family caregiving; (8) authorize and appropriate funding for a National Resource Center on Caregiving (FCA, 2007). Policy agendas such as these serve to raise awareness of key issues and provide a focus for action.

Universities are also contributing to rural policy development. At the University of Nebraska Medical Center, the Rural Policy Research Institute's Center for Rural Health Policy Analysis convenes the Rural Health Panel, which provides a crucial evidence base for policy development. Examples of other key universities contributing to the science of rural health issues include the University of Minnesota Rural Health Research Center, Institute for Health Services Research, in Minneapolis, and the North Carolina Rural Health Research Program, Sheps Center for Health Services Research, at Chapel Hill.

Service Provision

Professionals who work with aging populations appreciate the value of unpaid caregivers. However, before Congress recognized caregivers by passing the NFCSP, federal and state policy gave little attention to their worth, health, and well-being (Greene et al., 2011). Policy is needed that supports the continuation and development of family assistance and support programs such as the NFCSP.

Policies must take a more family-oriented approach that allows parents to be the caregivers of their young children without jeopardy to employment and economic stability. To that end, flexible work paradigms and leave policies should be crafted. For instance, some programs, such as the At Home Infant Care Program, pay parents a care subsidy when they choose to provide home care for their child rather than employing an external care provider. Such programs could be used as models for national policy. International models could provide data on the benefits and challenges of infant and child care.

Realizing the challenges of rural care delivery, state policy makers are engaging in regional and state planning. For example, Georgia (Greene et al., 2011) adopted positions calling for the design and implementation of services that support both caregivers and care receivers by linking easy access to services with consumer self-direction. Enhancing policy to include the use of Area Health Education Centers for ensuring a distribution of professional caregivers across a catchment area might also prove beneficial (Calico, 2011). The adoption of technology-friendly policies that support telehealth delivery systems for physical and mental health services are being integrated into many delivery plans. Further, Walker & Reschke (2011) call for states to adopt policies and provide resources, such as transportation, to further develop and evaluate rural preschool and after-school care programs.

Appropriation and Other Financial Issues

Funding is a key issue in addressing the needs of rural caregivers. In rural America, where there are an insufficient number of professional caregivers, policy is needed to support reimbursement for relative caregiving. Several options for reimbursing caregivers to provide home care have been developed. Vouchers, cash allowances, and tax exemptions, deductions, and credits have been proposed as a means to support rural family caregivers (Chwalisz, Dollinger et al.), although these proposals have met with resistance from legislative bodies. For example, the *Lifespan Respite Care Act of 2006* was passed by the US Congress, but was not funded for 3 years, until March 11, 2009, when President Obama included $2.5 million for it in the FY 2009 Omnibus Appropriations Bill.

Consumer-directed care policy also has been proposed because of its cost-effectiveness when compared with agency-based or nursing home care. Provider resistance, regulatory language, and quality issues have deterred the adoption of this model in some locales. The study of current consumer-directed care sites and wide dissemination of resulting evaluation data are proposed to inform policy makers of the value of this family friendly intervention.

Extant challenges to providing rural caregivers with training, technology, and community planning funds are daunting. Greene et al. (2011) propose several possible solutions: (1) federal–state matching compensation programs; (2) a base state budget for the provision of rural services; and (3) a weight factor for rural land mass in state allocation formulas. Policy makers must be informed about the compelling need to fund research on intervention development and evaluation, and provide support for knowledge transfer and replication to states and local communities (Calico, 2011).

Policy makers must delineate reimbursement strategies for physicians and other health providers who provide telephone, e-mail, or other forms of Web-based communication with both care recipients and caregivers. Further, as professional caregivers are encouraged to implement systems for electronic scheduling and person-centered records, compensation schedules that reward them for doing so are needed to expedite their adoption and reinforce new behaviors.

Higher reimbursement schedules for rural professional caregivers could provide one solution to workforce shortages and training deficits. To this end, policy that directs Medicare, insurance firms, and other reimbursement entities to increase payments to rural providers trained in geriatric care is proposed. One option might be the creation of a congressional commission charged with development of an improvement program for rural health-care quality and implementation of rural demonstration projects in quality service and training (Calico, 2011).

Workforce

Polices that support training, transportation, housing, and attractive employment and advancement opportunities for professional caregivers provide a foundation for a strong rural health-care workforce (Wilken & Stanback, 2011). These factors help motivate young adults to continue rural residence rather than out-migrating to more enticing employment settings. Numerous examples of incentive programs for workforce development are found in recent health-care reform legislation, the *Patient Protection and Affordable Care Act of 2010* (Public Law 111–148). The Act includes grants, subsidies, and loan forgiveness programs for specified groups of health-care providers, student subsidies through institutions of higher learning, and funding to encourage retention of health professionals. Section 5312 of the Act authorizes $338 million in appropriations to carry out nursing workforce development programs that include workforce diversity grants.

In another example, psychologists are trying to meet rural caregiver mental health needs by expanding their credentialing to include psychopharmacological prescription privileges. Currently, family physicians, who usually receive cursory mental health training, are the primary medical resource for rural residents. While they are increasingly cognizant of the effect of mental health problems on lifestyle and chronic illnesses, family physicians' lack of training in co-occurring conditions, such as depression, can lead to underdiagnosis and misdiagnosis. To date, New Mexico has passed prescription privileges for psychologists and in Hawaii, Louisiana, Mississippi, Montana, Tennessee, Missouri, Oregon, Georgia, and Illinois, legislation is pending. While insurance companies are increasingly providing at least partial reimbursement for psychological and behavioral health services, federal advocacy for full parity with physical health coverage has continued with introduction of the *Mental Health Parity Act of 2007* in the 110th Congress.

For family caregivers, benefit and insurance issues are critical. Currently, many family caregivers and home health workers provide "full-time" services without the benefit of Social Security contributions or health-care insurance. To maintain and increase the workforce that serves rural America, these concerns must be addressed. One plan that might serve as a state model, the *Healthcare for Montanans Who Provide Healthcare*, is an example of incentivization for employers to offer health insurance to home-care workers. Similar and expanded state models might provide relief for home-based caregivers, as well as those in the formal workforce.

Businesses also are developing innovative policies that will provide support to caregivers. In an one such move, McGraw-Hill extended their employees' health-care insurance to include parents of employees, in addition to their children (who were already covered) (Jamieson & Yeo, 2007). Through a pioneering program, many retirees, regardless of age, will benefit from the availability of health insurance, regardless of preconditions, that will be available in 2008 to over 250 businesses represented by the HR Policy Association (2007), including General Electric, IBM, Sears, Starbucks, and United Parcel Service.

Thus, employers who recognize the stresses their workforce caregivers face can respond with education, training, and support. While this training might not be delivered in the rural caregiver's home community, it does provide a glimpse of what businesses can offer in the work setting that might have benefits for employees residing in rural areas. Further, because a portion of the training that businesses are now promoting is Web-based, there is the potential for large companies to share these products with small, rural ones that otherwise would never be able to afford the benefit.

One new benefit change for rural caregivers who commute to work in metropolitan or urban areas is the provision of "caregiver wellness" programs by their places of business. IBM, Exxon Mobil, Texas Instruments, and Raytheon have all implemented caregiver wellness programs as a part of their elder care benefits (Shellenbarger, 2007) and United Behavioral Health, an employee assistance program, has documented a dramatic increase in the number of businesses requesting these services. Another employee assistance program provider, Ceridian, is providing a new telephone service: monthly caregiver support groups to address stress management and skills training.

Many caregiving issues deserve the attention of our nation's policy makers. Respite care funding, support for research on caregiver interventions and training, and incentives for rural and geriatric training and service by professional caregivers are all important issues. Rural health advocates must engage in advocacy with legislators at all levels of government. While dwindling tax bases and trends in out-migration, which lead to fewer rural residents, create an increasingly smaller number of rural community care advocates, their voices are helping policy makers understand that caregiving is an intense, multifaceted family issue. Although policy changes are usually slow and incremental, continuing advocacy on the many policy issues mentioned throughout this volume will be important if we are to meet the needs of rural caregivers.

Concluding Comments

The time has come to move our nation's rural caregiving services from a patchwork of disparate, uncoordinated, and often ineffective programs to a quilt of coordinated, tailored, effective, and responsive community services. For the sake of rural caregivers and their care recipients, county and local governments and agencies, including the health-care, mental health, aging, education, social service, and public health systems, must set aside historic differences and embrace a flexible, systemic approach to creating, supporting, and sustaining effective caregiver interventions. A life span approach to caregiving that embraces families caring for young children, people of all ages with disabilities, and the vulnerable elderly must be championed by leaders who implement policies that support quality, comprehensive planning, service delivery, and evaluation. Rural caregivers, who provide so much under challenging circumstances, deserve no less than our best efforts.

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