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Guest Editor's Message: Care Management and Rural Health Care Delivery

Lenard W. Kaye, D.S.W.

For geriatric care managers, rural practice may truly be the last interventive frontier. While I have less and less difficulty over the years referring family members, colleagues and others seeking the help of a geriatric care practitioner to such professionals in urban and suburban regions of the nation, trying to locate specialists in rural America can be an exceedingly frustrating task. The scarcity of a wide range of well-trained health and human service professionals, including care practitioners in non-urban regions of America, is becoming well documented. In some cases the problem is reaching crisis proportions.

I have spent the past year and a half in Maine and can speak from experience concerning the severity of this geriatric human resource problem. The paucity of geriatric care practitioners in rural communities, coupled with the special challenges facing older adults and their families residing in these parts of the country, can make life especially challenging. Economic hardship, inadequate housing, geographic isolation exacerbated by transportation barriers, out-migration of younger generations, poor employment prospects, a deteriorating infrastructure magnified by inadequate numbers of seasoned human service professionals, combine to make life for older adults a hardship.

Nurses, social workers and others with pioneering spirits must be willing, in greater numbers, to reside and establish care management careers in non-urban communities. Those who accept the challenge, should be prepared to be ambidextrous professionals, dealing with unanticipated obstacles, large and small. Practice flexibility, a multi-disciplinary orientation, and comfort with role ambiguity are extremely valuable qualities in rural practice. Such workers will also need to make special efforts to understand the culture, concerns and needs of older rural persons. To compound these challenges, be prepared for many rural residents, elders especially, to display a "stiff upper lip" mentality and a fierce independent character. They may be hesitant to consider utilizing the services of a geriatric care manager even if such services are needed, available, and affordable. My intent is not to perpetuate a stereotype, but to inform practitioners of a cultural tendency that shapes, but does not necessarily interfere with successful intervention.

Nurses, social workers and others with pioneering spirits must be willing, in greater numbers, to reside and establish care management careers in non-urban communities. Those who accept the challenge, should be prepared to be ambidextrous professionals, dealing with unanticipated obstacles, large and small.

Special obstacles for rural vs. urban geriatric care practitioners include the likelihood that rural providers will confront many challenges; Higher levels of poverty, illness and disability, less numerous and accessible health and human services, the absence of a continuum of care, extremely isolated family caregivers with few reliable formal supports and geographic isolation. Higher proportions of rural elders are in poor health in comparison with their urban counterparts. In a rural community, fewer alternative living arrangements and respite services can force family caregivers to choose between care at home and institutionalization for their elderly relatives. The trend of out-migration by young people in small communities has resulted in further depletion of the availability of relatives and other informal supports to care for older adults (Kaye & Sherman, 2002).

Rural geriatric social workers must be willing to reach out actively to their clients. The most successful rural geriatric care managers spend little time behind their desks, as they are in their cars traveling frequently to distant addresses. They are also making use of the latest technology that allows them to establish on-going connections by any means necessary in performing their tasks. Traditional clinical and non-clinical sessions held at centralized office locations have little utility in many instances. Rural elders especially rely on social services that are decentralized and mobile. It can be costly to deliver

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services in rural communities due to distance between providers and recipients. In addition, rural providers cannot benefit from economies of scale to the degree that urban providers can, given the relatively smaller numbers of rural consumers of health and social services. The greater costs of delivering services to rural elders is specifically reflected in home-based interventions that appear to be difficult to support in low population density areas.

More than eight million adults live in rural America. They deserve access to the skill set offered by trained geriatric care practitioners. If more professional geriatric care managers were willing to establish residence in rural America, they would not only capitalize on the need for their expertise, but also find the quality of life that a close knit and caring rural community can provide. Working in rural America can mean living in a safer environment, with strong sense of community and where people have the time and inclination to be friendlier and more concerned for their neighbors. I can tell you from my newfound experience, it can make for a very satisfying life.

In this special issue of the *GCM Journal*, a group of superbly qualified practice educators address the specialized issues and challenges of rural care management service delivery. There is much to be learned. Please take the time to read each article carefully.

Eloise Rathbone-McCuan enhances our discussion with special attention directed at matters of rural geriatric mental health. In the absence of a national rural mental health policy, Rathbone-McCuan paints a vivid portrait of geriatric mental health service scarcity in rural America. She suggests that care managers and other health professionals not only need to build expertise in geriatric mental health practice but, should also be willing to strategically lobby and engage in similar such advocacy efforts on behalf of their clients.

Angeline Bushy, who has recently published a book on rural nursing, highlights in her article three ethical situations that actually occurred in a rural health care setting. The purpose of the article is to create awareness among geriatric care managers so they can recognize, perhaps prevent and, if necessary, respond appropriately to bioethical situations that may arise in rural practice.

Drawing on data from a survey of older adults in rural Maine, my colleague **Sandra Sue Butler** underscores a major concern voiced by those who study the current status of geriatric home health care services. Her data highlights an inadequate and unreliable system of home-based interventions in rural communities, that may accelerate decisions to institutionalize older adults even though we know they would much prefer to remain in the familiar settings of their own homes. Butler identifies the chronic flaws in our system of community-based care and suggests strategies for addressing such concerns.

Lorraine Dorfman provides us with an extremely thoughtful and sophisticated analysis of the contributions made by relatives in supporting rural elders. She correctly highlights the diversity of rural elder populations and the need for expanded service options and improved coordination of formal and informal systems of care. Her observations of family structure and function in rural communities are most intriguing.

Linda J. Redford and **Steve Corbett** close this issue with a rich and comprehensive offering of critically reviewed print and electronic resources for geriatric care practitioners. This guide is thoroughly prepared and will surely prove to be an indispensable reference for care management practice.

Lenard W. Kaye, D.S.W. is a professor at the School of Social Work, director of the UMaine Center on Aging, University of Maine, in Orono, ME and also serves on the GCM Journal Editorial Board.

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Perspectives on Rural Mental Health Services: Limited Options for Older Persons

Eloise Rathbone-McCuan, Ph.D., M.S.W.

The United States faces a geriatric mental health care crisis that has been building as the American population ages, (Jeste, 1999). There are different levels of unanswered service needs that distinguish the rural elderly concerning the availability of diverse and appropriate services. Some of the frequently discussed strategies needed to expand and improve the scope of mental health services to older Americans include:

1. Developing social policies that build better integration between primary health and mental health services.
2. Expansion of community-based in-home services with more attention to in-home counseling for elderly patients who are restricted to home.
3. Increased training opportunities in geriatric mental health specialties.
4. Broadened mental health advocacy base for expanded service capacity in the public and private sectors through mental health reimbursement parody.

If implemented, these strategies could more easily influence service expansion in rural areas. Better primary health and mental health care integration assumes the availability of both services in a common geographic area. Unfortunately, many rural communities lack both care resources. Funding for expanding in-home services with a mental health service for counseling and intensive case management are difficult to support in low population density areas. Trained geriatric specialists cluster their professional practice base in urban communities and have few incentives to work in rural areas, unless they are returning to their home communities after training (Ricketts, 1999). Advocacy networks of and for older persons are much more active in large metropolitan areas as compared to rural communities due in large part, to the difficulties associated with building and sustaining these networks in smaller communities.

National attention given to issues facing rural America tends to concentrate on a range of economic issues. Large agricultural business corporations dominate many areas of domestic food production. Federal government debates about changes in farm subsidies ebb and flow. Plans to regulate and manage the supply and demand of migrant farm labor is yet unresolved in many parts of the country. The inadequate transportation infrastructure in rural areas remains an ongoing and unresolved priority. Urban expansion for new residential demands is changing the rural landscape in every region. Unfortunately, human service resource challenges seem to have faded from view, being replaced by rural markets and economic growth priorities.

An Earlier Era Of Rural Community Mental Health Centers

National policy directives to create comprehensive noninstitutional mental health services were on the agenda of the first Community Mental Health Centers Act of 1963. Older adults were designated within the Act as a special at-risk population. They were to receive a continuum of mental health services encompassing outreach, prevention, education, treatment and consultation services as the community mental health centers became operational. Outreach services were essential to the isolated elderly and their families to make them aware of the specialized mental health services offered at centers. Prevention and education services were given priority. Both these services promote successful aging and reduce misinformation and stigma about mental health needs and services. There was growing professional understanding that psychotherapy was beneficial, thus individual and group counseling options were considered valuable approaches for older clients. The expansion of nursing homes, congregate senior housing, Area Agencies on Aging, and comprehensive senior centers were authorized in the Older Americans Act of 1965. These newly served groups of older people and some programs could be developed with mental health consultation.

A small proportion of the community mental health centers that were established during the late 1960s were never in a position to implement the range of services considered necessary for older persons. The original community focus of mental health centers became redirected as the result of pressures of the nationwide trend toward psychiatric hospital deinstitutionalization. This large movement of inpatients from state psychiatric hospitals forced a shift in priorities. It was necessary for center staff to redirect themselves to provide community placement planning and monitoring, and crisis intervention. Services to this population set the foundation for case management functions for those with severe and persistent mental illness. A significant number of state mental hospitals were located in rural areas. The impact this trend extended onto rural community health centers over thirty years ago greatly limited capacity to deliver mental health services to the original target populations. The impact on the rural elderly was to remain without accessible and affordable regional mental health center services.

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The Rural Physician as a Mental Health Gatekeeper

Many rural residents must rely on their rural physician as a mental health gatekeeper. These physicians are too often the first frontline treatment provider to identify and respond to an older patient's mental health problem. At the same time, the establishment of strong physician-elderly patient relationships involves years of medical care provision and trust-building. Older patients, to various degrees, are willing to share information about stress, mood changes, shifts in memory and recall, and possible symptoms of depression. Yet the size of the patient practice of most rural internal medicine specialists and small family medicine group practices is very large. Setting aside time for counseling patients of any age,who exhibit emotional distress is often very difficult. Mental health referrals for rural patients to qualified professionals within reasonable distance are difficult, if not impossible to make, compared to the options available in urban areas. Keeping abreast of the rapid proliferation of the newest and/or most beneficial prescriptions for depression and other illness symptoms is also a difficult challenge for rural mental health professionals who don't have the options of engaging in specialized geriatric care practices. Finding the best drug combination for elderly patients with psychological symptoms that interplay with chronic illnesses and disability may also be especially difficult to monitor in rural settings because of the distance between patient and provider. Inadequate follow up of psychotropic prescriptions poses yet an additional threat to older persons in non-metropolitan areas.

One rural physician's comments reflect one viewpoint of the mental health needs among elderly patients. She notes:

"It is fairly common that older patients will experience depression over the losses they experience. Life times of productivity leading to acquiescence of later life limitations is especially hard for older people who have no retirement transitions similar to the typical older urban couple."

The importance this physician places on listening is significant.

"I listen as carefully as possible during the short time I see my older patients for signs of emotional problems. I won't prescribe medications if I feel the patient's struggle is one of normal adjustment to conditions they have to live with unless I am seeing a person with a clear dysfunctional mood."

Mental Health referrals for rural patients to qualified professionals within reasonable distances are difficult, if not impossible to make, compared to the options available in urban areas.

An elderly rural widow patient of the above mentioned physician, spoke of dark days she faced. Her perception of her life makes it difficult to know if she suffered from depression.

"So many of my days loom long. When I ache too much I have to push myself to stay out of bed. My pain is too plentiful and sometimes it feels like it starts from the inside and works its way out. So, I just have to wait that day out. Sometimes when my old friend, my friend for sixty years, calls me, I get to feeling better because she has big troubles with her health and all her kids. We talk more about her kids and that is much better than talking about our lives in the junk heap."

This elderly woman's quality of life was seriously compromised. Her life was inactive, lonely, and she felt overwhelmed by pain. It is unclear whether she was clinically depressed or coping with negative life circumstances. It was unlikely she would entertain the idea that she was depressed. In her view she was living through her old age as best as possible in her circumstances. It is likely that she might take a written prescription for a mood medication if her physician insisted, but would not have it filled herself. Many elderly people have no faith that mood changing drugs will make their life better and, in fact, fear their use will make things worse.

This woman had adult children living in other states who were almost at the point of trying to force her to relocate to their communities. This was the option considered workable to both of her adult children, but their mother would give no consideration to relocate from her small hometown of 82 years. She didn't have any intention of arguing this decision with her children and felt anger toward them because of their persistent pressure.

This situation is such that a physician is likely to be cautious about a quick prescription solution. Adult children at considerable distance may ask the parent's physician to intercede with older family members. In the above case, one of the adult daughters contacted the physician several times with requests to intercede with full support of relocation. The physician was unwilling to do this for several reasons: 1. The physician felt there was no immediate medical care reason for the widow to move. 2. The patient would have felt betrayed if she thought her physician had conspired against her. 3. The probable arrangement put in place by either daughter

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would have involved efforts for an inappropriate nursing home placement.

Families frustrated over an older person's independence often have a long history of very poor communication and conflict. Control is an all too common aspect of handling difficult situations among strained intergenerational relationships.

An Example of Effective Family and Community Provider Efforts

Practitioners treating depression among older persons are aware of the frustration and confusion it often creates within the caregiving social network. Behavioral and mood changes, denial or fear of meaninglessness and obsessions of helplessness warrant attention. The appearances of symptoms emerge differently among older persons and sometimes only a crisis event produces long needed intervention.

The case illustration described below involves a combination of symptoms. These symptoms are not understood as manifestations of prolonged depression. Conditions of mood and behavior are assumed to be part of the normal grieving process. It also demonstrates how the limited resources in a small rural community can cooperate to get an elder much needed formal short-term mental health treatment.

"My husband's youngest brother Luke, about 18 years younger than us, was killed in a farm accident almost three years ago. This death left everyone in our families at a total loss. For John, his brother's death represented a loss of deep meaning as he had almost raised Luke and moved him toward full-time farming after his dad's death in middle age. At a really young age, Luke was gaining financial success and John and Luke worked as partners for quite a few years until John's heart attack led him into semi-retirement. Reality drew him away from operations of the local farms we had incorporated. I knew John felt some guilt about Luke's death as an accident that might have been prevented if there had been a second person operating the machine. On the First Anniversary of Luke's death we had organized a morning memorial service at grave-site and a Pancake Memorial Breakfast for the family and church members. I woke up early and immediately realized that John had never come to bed the previous night. I knew something was bad, and so I started calling and knew he wasn't in the barn. I guessed right. I found him in our pony barn sitting on a bale of hay with one of his shotguns cocked sitting next to him."

This case narrative was an example of the best of mental health interventions when the formal and informal care giver networks can move quickly in a coordinated and supportive approach to help the at-risk person. John's pastor and physician took steps with John and consulted with the family as to how to be watchful for other signs of self-harm. The physician referred John to a therapist with a private practice in a town about 30 miles away. This was a referral made to a clinician who had treated a suicidal teenager under the doctor's medical treatment a year before. The family pastor had several visits with John and encouraged John to give the therapy a chance even if his only motivation to start it was for his family. The therapist tapped into John's deep feelings of guilt that he had not assumed responsibilities for helping his sister-in-law run certain farm operations. Part of the early therapy was to support John to move into the business management side of the farm. That required him to learn computerized financial management programs. John learned this quickly and later expanded his goals to begin stock investments to build a college fund for Luke's two young daughters. The efforts of each person represented a sort of "wrap around" intervention making use of both the formal and informal provider resources.

Conclusion

At the beginning of the 21st century there is still no national rural health policy. There has been massive restructuring of the country's health care system. The development of managed care has shifted approximately 20 percent of the rural elderly in to health maintenance organizations (Rosenthal, 2000). This should not lead to the assumption that older persons requiring intensive or long-term mental health care will fare well in this era of managed care (Jeste, 1999). There continues to be differential Medicare payments that amount to about 35 percent less Medicare reimbursements for rural physicians and hospitals compared to both urban providers and medical settings.

Several developments may stimulate some improvements in the availability of rural health and human services. The U.S. Department of Health and Human Services established a new comprehensive agency task force that will examine how rural communities are faring in the health and human service areas. Again, the rural elderly will be identified as a population at-risk. Their risks are the lack of accessible services across all health and social service delivery areas. The current devolution of federal social policy authority to state government is important. This shift may have a notable advantage to rural communities if rural legislators are an influential political force. Well-planned lobbying efforts for major health and human services need to become an important political issue.

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Ethics: What Geriatric Care Managers in Rural Practice Should Know

Angeline Bushy, Ph.D., R.N., C.S.

Introduction

Rural geriatric care managers are not exempt from ethical conflicts. The rural population is older than the urban population having a median age of 36 years compared to 34 years for urban areas. The older population accounts for 18 percent of the population in rural counties and has grown as a result of both the entrance of retirees and the exit of young adults (NRHA, 2000). To demonstrate relevance, the following three cases occurred in rural health settings. Names, places and outcomes have been modified to assure anonymity and protect confidentiality of those involved (Bushy, 2000). Most readers, however, will be able to describe similar cases that have presented themselves in their own practices.

- Greg, a 47-year-old fisherman was diagnosed as having a positive blood test for AIDS. He is not surprised and insists that the physician not inform his wife of the lab results. The couple has been married for eight years and has two school-age children. Greg's mandate is in direct conflict with the physician's belief regarding the right of a spouse to be informed when a patient has a positive HIV test. How should the doctor handle Greg's request in light of his conflicting professional views?
- Lucy, 92 years old, suffered a severe heart attack three weeks ago. Since then she has been comatose and fed through a gastric tube. Recently, her family demanded that tube-feedings be discontinued in order to respect Lucy's verbal request of: "When the time comes — let me die in peace." Her two daughters do not believe their mother has a living will. How can Lucy's wishes be carried out without ethical and legal repercussions?
- Steve, 59 years old, was transferred from a large hospital on the West Coast to a very small hospital in his hometown. He has not lived here for more than 30 years. His diagnosis is advanced cancer of the pancreas. The community "rumor mill" attributes his emaciated condition to advanced stages of AIDS. Several local residents are questioning whether or not it is safe to be admitted as a patient to their local hospital. Currently, this facility is experiencing "financial problems" related to low patient census and the effects of the Federal Balanced Budget Act. How should the hospital's administration respond to the community's (mis)perceptions regarding this particular patient while protecting the survivability of the facility?

These three situations reinforce that rural as well as urban-based geriatric care managers encounter ethical situations, perhaps more often than they care to admit. Certain dimensions related to residency can influence the manner in which ethical situations are resolved. For instance, rural residents sometimes are described as family-oriented and have better access to extended kinship networks. Conversely, familiarity coupled with limited access to health care, as often is the case in rural settings, may contribute to the complexity of an ethical situation. Factors such as these can facilitate, and sometimes hinder, consensus about the most appropriate intervention for a client and his or her family (i.e., client system) who are involved in a real or a potential bioethical situation (Gropper & Giovinco, 2000).

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Promoting Ethical Awareness

Whenever feasible, geriatric care managers should participate in interdisciplinary ethics discussions. Unfortunately most have not had a formal ethics course in their programs of study. Furthermore, those in rural communities may not have access to continuing education (CE) programs on the topic of ethics. In spite of these educational limitations, geriatric care managers in rural as well as

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urban settings must become aware of ways to prevent, recognize and intervene in ethical situations.

Awareness can begin by becoming familiar with basic ethical information and the ethical decision-making process (Figure 1). Discussing seemingly abstract ethical concepts with peers is one strategy to glean clinical insights about bioethics. Even more fundamental, though, is reflecting on personal beliefs regarding health, illness, care seeking behaviors, death, dying and one's professional scope of practice (Monagle & Thomasma, 1998). A self appraisal includes comparing and contrasting personal perspectives with the Geriatric Care Managers' Professional Code of Ethics; that is, congruencies and differences between the two are acknowledged. Subsequently, one ascertains how personal and professional values fit with the mission of the employing institution. The appraisal process prepares the geriatric care manager to recognize potential ethical situations in one's practice and, hopefully, prevent such situations from becoming a "full blown" bioethical dilemma. Prevention strategies, for example, could include educating the public on the need for advanced directives, and insuring patients who are admitted to acute and extended care facilities have the supporting legal documentation such as a living will and a designated power-of-attorney (McMahon, 2001).

Bioethics Committees

The complexity of most bioethical situations mandates that a number of individuals having different perspectives participate in discussions to resolve a case. One or two people cannot anticipate the full legal, ethical or medical ramifications of these complex situations. A bioethics committee provides an arena for interdisciplinary discussion regarding real or potential ethical situations that may present in a health care facility, such as the three cases introducing this article.

Membership varies from institution-to-institution, but bioethics committees usually include a physician, lawyer, ethicist, administrator and other types of health professionals. Not every discipline can, or will, be represented on the committee but multiple perspectives must be considered. In rural areas, health care providers are more apt to be personally acquainted with clients - as friends, neighbors, or relatives. As such, informal connections provide more opportunities to become knowledgeable about a client system's expectations and preferences regarding health care and what constitutes a "quality life and death." Conversely, familiarity with those involved can hinder a professional's objectivity about the case and may pose threats to maintaining anonymity and confidentiality when participating in formal ethics discussions.

Very small hospitals generally do not have a "formal" (bio)ethics committee in place. Hence, professionals in those settings should be familiar with a nearby facility that does and/or someone who is able to provide ethical consultation should an in-house case occur. When a small hospital is part of a health care system the ethics committee may be housed within the largest urban-based tertiary medical center. Sometimes several small facilities within a geographical area collaborate and establish an ethics committee to deal with situations that present in participating institutions. On occasion, one or two health professionals have been instrumental in implementing an ethics committee in remote rural facilities (Bushy, 2000).

Regardless of size or location, it is prudent for an institution to have access to a functioning ethics committee **before** there is a need for one. When a potential ethical situation arises in the clinical setting, it should be referred by a health professional to the bioethics committee according to the institution's policy and procedures. Upon receipt, the committee determines if the case has medical and/or legal ramifications and, if so, expert consultation is sought regarding those issues. Applying various ethical principles, the case is analyzed to determine the various options (interventions) along with potential consequences for each (Figure 2). Essentially, the committee determines if the outcome(s) of an intervention will support the person's wishes, increase or decrease patient and/or family suffering, improve their quality of life, postpone death, or be the proximate cause of death.

Most bioethics committees have an educational component. Education can go a long way to promote ethical awareness among the public, health professionals and geriatric care managers; perhaps, preventing bioethical conflicts from occurring (Combs, 1996; Noland, 1998; Olson, 1998; Rushton & Sabatier, 2001).

Concluding Comments

Space constraints limit extensive discussion related to ethics principles and ethical decision making. Geriatric care managers are encouraged to seek out textbooks for detailed information related to ethics and bioethics committees. A comprehensive discussion of the three cases that introduced this article is not feasible here, but these could be a starting point for interdisciplinary discussions on various ethics topics. A few concluding general comments about ethics situations are offered for reader consideration and to evoke further interest in learning about ethics.

- Undoing a treatment after it has been started, can pose ethical and or legal dimensions that may not have occurred by initially withholding the intervention. For instance, it may be more appropriate to withhold a feeding tube, not start chemotherapy or not place a ventilator on a very seriously ill patient than to discontinue the intervention *after* it was started. Withholding treat-

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ment must, therefore, also be considered as an intervention option in ethical decision making.

- Effective communication with client systems and other health professionals can go a long way in preventing bioethical conflicts from occurring. Geriatric care managers must be sensitive to a client system's beliefs about health care and surrounding death and dying. For instance, extended family may want to care for their gravely ill loved one at home or have a cultural healer intimately participate in the care plan. Cultural beliefs not only influence health care preferences but also how one defines "quality" of life. A client system's views may or, may not be congruent with those of technologically-oriented health professionals. When differences are not reconciled, conflicts can arise about the appropriate care for a family member (Erlin, 1998).
- An important aspect of an ethical case is identifying the "patient" and who is responsible for making decisions; for instance, as in the case of a mentally ill adult, a child or someone having high doses of analgesics. Many ethical situations might be avoided or resolved more quickly when a client has prepared advanced directives. However, family members as well as caregivers must be aware of those wishes and that legal documents are needed to carry out the person's preferences.
- Health professionals in general, and rural geriatric care managers in particular are in an ideal position to recognize potential

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FIGURE 1:
Overview of Ethical Decision-Making Process*

Process	Actions
Promote & Develop Awareness	Complete self appraisal of personal values and beliefs
	Educate health professionals and community
	Compare personal values and beliefs with geriatric case manager's professional code of ethics
	Assess congruence with an (employing) institution's philosophy and mission
	Recognize real or potential ethical situation
	Make appropriate referrals to institution's ethics committee
Assess Situation & Define Problem	Determine if it is an ethical, legal, or medical situation, or combination thereof
	Seek expert consultation
	Identify the patient(s)
Collect & Analyze Data	Collect data (i.e., advance directives, legal statutes, etc.)
	Analyze case using ethics principles
	Identify all options/interventions
	Consider all real and potential environmental influences for each treatment option (e.g., legal; client system values; community standards)
	Appraise benefits & risks for each member of client system , community, and providers
Select & Implement Intervention	Identify the "best" or most appropriate intervention
	Implement action
Evaluate Process & Outcomes	Process evaluation (formative/on-going evaluation of the process and system infrastructures)
	Summative (outcome) to determine appropriateness of action and the functionality of ethics committee
Educate Professionals & Community	Health professionals using actual and/or potential case analysis to review outcomes in relation to prevention strategies, recognition of potential problems, ethics principles, application of ethics concepts
	The community, i.e., need for/process to complete advance directives; realistic expectations from health care provider etc.

** Adapted from Bushy, A. (2000). Orientation to nursing in the rural environment. Thousand Oaks, CA: Sage Publications*

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ethical situations because they tend to directly interact with a client system. Prevention is the best approach. However, should an ethical situation arise providers should be familiar with resources that can help them to deal with the case. It is of utmost importance to know how to make referrals to a bioethics committee.

- Clinicians providing primary care should make a dedicated effort to educate adult clients about the need for advanced directives. They also must be able to refer them to someone who can assist them in completing the process.
- Administrators must assume the initiative to prepare employees to recognize real and potential ethical situations. This could include inviting an outside speaker to talk on ethics related topics, providing opportunities for interdisciplinary ethical discussions and arranging for an expert to facilitate the analyses of actual or hypothetical cases.

Finally, regardless of the setting, be it rural or urban, ethical awareness programs must start **before** situations like Lucy's, Greg's and Steve's arise, and geriatric care managers are in a position to be of help in bringing this about for their clients and among their peers.

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FIGURE 2:
Examples of Ethics Principles*

Ethical norm	A statement (principle) that actions of a certain type ought (or ought not) to be done
Autonomy	Respect for individuals who act autonomously (not others) to make decisions that effect their lives
Paternalism	Limiting an individual's liberty when his/her actions might result in harm, or fail to produce an important benefit
Beneficence	Act(s) of kindness; an obligation of doing or promoting good for another Do no harm; maximize possible benefits and minimize possible harm
Utility	The greatest good/happiness for the greatest number
Justice	Equals should be treated equally; those who are unequal should be treated differently according to their difference

** Adapted from Bushy, A. (2000). Orientation to Nursing in the Rural Environment. Thousand Oaks, CA: Sage Publications*

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Family Caregiver Experiences with Professional Home Care in a Rural State

Sandra Sue Butler, Ph.D

Introduction

This article reports on a recent examination of rural family caregivers' perceptions of professional home care, and the extent to which inadequate and unreliable home care contributed to the family decision to move the patient to a nursing facility. The State of Maine, the site of this study, is committed to improving community-based care for elders, and reducing over-reliance on nursing facilities. Similar to many rural states, Maine has tended to have a higher rate of nursing home placement among the elderly than the national average—6 percent vs. 5 percent, respectively, in 1990 (Mageean, AvRuskin, and Sherwood, 2000)—and has been working to change this trend in the past decade.

While available anecdotal evidence indicated that families caring for frail elders at home often became frustrated by problems such as home care workers arriving late, changing frequently or abiding by family requests, a systematic exploration of this issue had not taken place in the state prior to this study. In collaboration with Maine's Bureau of Elder and Adult Services (BEAS), the Maine Alzheimer's Project and with support from the Margaret Chase Smith Center for Public Policy, I investigated this issue via a mail survey to family caregivers of all individuals who were admitted to nursing facilities in Maine over a three-month-period (April through June, 2000), and for whom we had current information on their family caregiver.

Maine is a rural state. There are only three metropolitan areas with populations greater than 25,000—Portland, Lewiston and Bangor. Other "urban" areas consist of incorporated cities and census designated areas ranging in population from 2,500 to 25,000. Access to social and health services is more limited in these small and mid-sized towns than in the three larger cities. At twice the national average, half of Maine's elderly live in rural areas, towns of 2,500 or less, which have even more restricted access to health and social services, (Mageean et al., 2000). Frail rural elders in Maine, like others in rural areas throughout the country, face some unique challenges specific to their relative geographic isolation.

Access to Services in Rural Areas

As a result of aging-in-place, out-migration of young persons and in-migration of older individuals, the elderly population has increased in non-metropolitan areas throughout the United States in the last half century (Rogers, 1999). Unfortunately, social and health care services for elders in small towns and rural communities are fewer and less accessible than in urban areas (Krout, 1998; Rogers, 1999). Krout and Coward (1998) describe the situation of rural elders as one of "Double Jeopardy" where there are higher rates of poverty, illness and disability among rural elders vs. urban elders. These are situations that are compounded by access to a smaller number and narrower range of health and human services.

Rural residents have significantly less access to home care than do urban residents. Moreover, rural home care agencies are less likely to offer auxiliary services such as social services than are urban agencies (Krout, 1998; Stoller, 1996). Rural areas often do not have the resources to develop a continuum of long-term care for frail elderly and it is frequently difficult to recruit health care professionals to rural areas (Krout, 1998; Redford, 1998). Some authors have hypothesized that this "death" of community home care has led to higher rates of institutionalization in rural areas (e.g., Krout, 1998).

Family Caregivers

Family caregivers form the backbone of this nation's long term care system. Caregivers provide unpaid assistance to loved ones with disabilities and chronic illnesses, and while this role is generally undertaken willingly, there are many emotional, physical and financial costs to the caregiver. There is a considerable body of research on caregiving burden. The responsibilities of caregiving appear to affect both the psychological and physical well-being of those individuals providing care (Green & Coleman, 1995). While it is widely acknowledged that there is variation in the degree of stress and burden experienced by caregivers, the caregiver role is often associated with emotional strain, negative feelings and depression (Zarit, Reever, Bach-Peterson, 1980).

In rural areas the difficulties in caregiving may be compounded by geographic distance from both formal and informal assistance. The narrower range of services in rural areas not only impacts frail elders, but also their family caregivers, who may receive less help with their caring work and experience more isolation than their urban counterparts (Botsford, 1993).

Professional Home Care

While both men and women provide informal care, women are more likely to be caregivers, to provide more hours of care and to provide care over longer periods of time. Similarly, professional home care is provided almost exclusively by women. Thus

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caregiving is often considered to be particularly a women's issue, and feminist scholars have cautioned that policy innovation in the area of long term care, both formal and informal, should place high value on gender justice among other considerations. The wage levels and work conditions of paid caregivers comprise one aspect of our long-term care system, which requires examination with a gender lens. The wages of paraprofessional home care workers; home health aides, chore workers, personal care workers and home attendants are at a poverty level and generally do not include benefits (Hooyman & Gonyea, 1995). A recent study by the Maine Health Care Association (1999) found the average hourly wage of Personal Care Attendants (PCAs) in Maine to be $6.28. Only eight percent of the study's respondents received benefits and nearly two thirds (61 percent) had received no wage increase with added experience. Nearly all the PCAs in this study were women (97 percent) and middle-aged (only 18 percent were younger than age 35).

Currently, Maine is hard-pressed to fill the need for home care workers. Between 1990 and 1997 overall employment in Maine grew by one percent, while employment among home health aides grew by 131.5 percent (Maine Health Care Association, 1999). Unfortunately, while the number of jobs in the state has increased dramatically, the labor force is no longer growing at the same rate; a growing demand for workers in the home health field is faced with a stagnant supply of workers in Maine. Future projections by the Maine Department of Labor are no rosier for the home health care industry. While home health aide employment is expected to increase by 82% over the next five years, these jobs will compete with other service industry jobs which are expanding in the state (Maine Health Care Association, 1999); competing jobs often pay more and are less physically taxing.

Given the often poor wages, stressful work conditions, and tight labor market, one might expect that the reliability and quality of professional home care work could be jeopardized. Such a situation would place additional strain on family caregivers, perhaps contributing to the decision to stop caring for their loved ones at home. The purpose of the study described herein is to explore this possibility in the rural state of Maine.

Method

During the months of April, May and June 2000, there were 725 admissions to nursing facilities in the state of Maine. Just under half of these admissions (n=358) had a listed caregiver; only 60 percent of these identified caregivers were based on enough current information to be used with confidence, reducing the number to 215. This number was further reduced when caregivers listed as professionals, such as physicians or caseworkers for the Department of Human Services, were removed (n=185). Additionally, five addresses were incomplete, leaving a final list of 180 family caregivers. The list of 180 individuals was chosen as a convenience sample of the population of caregivers who had placed a family member in a Maine nursing facility in the previous three months; the convenience sample appeared to be about half the population and had no particular, known bias. For purposes of this study, the phrase "family caregiver" includes friends as well as actual relatives to the person receiving care.

A six-page survey was mailed to the 180 family caregivers in August 2000. Survey questions explored reasons their family members needed care, reasons for nursing home placement, experiences with home care, experiences and desires concerning training in providing care and demographic information on both the caregiver and the care receiver. A cover letter accompanied the survey, explaining to family caregivers that we were very interested in knowing their experiences so that we could advocate for their needs. To protect the confidentiality of survey recipients, BEAS staff mailed the survey package to the family caregivers.

Forty-one completed surveys were returned representing a 22.8 percent response rate. Initially this low rate of return surprised BEAS staff, as the agency has traditionally received 50% response rates on surveys to caregivers. After some reflection, we realized that the recipients of this survey were no longer receiving services from BEAS and thus perhaps felt less motivation to participate in the study. The sub-sample of 41 was compared to the convenience sample of 180 caregivers on the one available variable: A relationship between the caregiver and the care receiver. Generally the sub-sample appeared fairly representative of the larger sample of 180 though some categories were more highly represented in the sub-sample of 41 (e.g., daughter and daughter-in-law) and some were less well represented (e.g., brother, sister and friend). See Table 1.

TABLE 1:
Comparison of Sub-Sample to the Convenience Sample on the Variable of Relationship

Relationship	Convenience Sample (n=180) %	Sub-Sample (n=41) %
Daughter	30.1	43.9
Spouse	27.2	22.1
Son	15.9	14.6
Brother	5.5	2.4
Sister	4.4	2.4
Friend	4.4	2.4
Niece	3.3	4.9
Daughter -in-law	2.2	4.9
Nephew	2.2	0
Other	4.9	2.4
Total	**100.0**	**100.0**

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Results

Sample description. Respondents to the survey ranged in age from 34 to 86, with a mean age of 57. Over three-quarters of the respondents (80.5 percent; n=33) were women. Fifteen percent of the caregivers responding to the survey had not completed high school, 45 percent had a high school diploma, and 25 percent had some post-secondary education but had not completed a degree; the remaining 15 percent had two-year, four-year, or graduate degrees. Nearly half of these family caregivers were employed outside the home (48.8 percent; n=20), and many had additional caregiving responsibilities for children (19.5 percent; n=8) and/or other dependent adults (14.6 percent; n=6). The respondents were generally quite low-income: nearly half of these caregivers had household incomes below $20,000 (47.2 percent), and less than one fifth (19.4 percent) had household incomes above $40,000. Well over half of the sample (62.5 percent; n=25) lived in rural areas (census designataed places with populations of 2,500 or fewer), 11 respondents (27.5 percent) lived in Maine's more urban areas (cities or census designated places with populations of 2,500 or more), and four respondents to the survey lived out of state.

The median age of the family member for whom the respondents had been caring was 83. About two thirds of these care receivers were women (65.9 percent; n=27) and 14 (34.1 percent) were men. The primary conditions listed for why their family members needed care were: stroke (43.9 percent), Alzheimer's disease or other dementia (39.0 percent), vision impairment (26.8 percent), diabetes (17.1 percent) and arthritis (17.1 percent). On average, caregivers had been providing care to their loved ones for nearly two years (median=32 months) before their family members moved to nursing facilities.

TABLE 2:
Reasons for Nursing Home Placement

Rated as "Very Important" or "Important" Reason	Number	Percentage
1. Declining health of family member	32	78.1%
2. Friends/relatives could not help enough	25	61.0%
3. Declining health of caregiver	22	53.7%
4. Incontinence	21	51.3%
5. Home care services were not adequate	19	**46.3%**
6. Could not afford home care services	18	**43.9%**
7. Difficult behavior	17	41.4%
8. Home care services were not reliable	14	34.2%
9. Recent fall or illness	9	22.0%
10. Life circumstances changed for caregiver	9	22.0%
11. Needed better place to live	1	2.4%
12. Home care services not available	1	**2.4%**
13. Family member could not be alone	1	2.4%

Reasons for nursing facility placement and experiences with home care. Caregivers were offered a list of reasons that might have contributed to the family's decision to stop providing care at home. They were also encouraged to describe any other reasons not offered on the survey. Conditions which respondents considered to be "very important" or "important" in their decision to move their family member to a nursing facility are listed in Table 2. The inadequacy (46.3 percent), cost (43.9 percent), unreliability (34.2 percent) and unavailability (2.4 percent) of home care services were important factors in the nursing facility placement decision for a substantial number of respondents.

Nearly three-quarters (73.2 percent; n=30) of the survey respondents had used professional home care to assist them in their caregiving. Twenty-one of these 30 individuals (70 percent) had used home care nurses and 27 (90.0 percent) had used other home care workers such as Personal Care Attendants (PCAs). In the month before nursing facility placement, home care nurses had been used, on average, for three hours per week, and other home care workers had been utilized for four hours per week, on average, by these respondents. The 11 respondents who had not used formal home care gave some of the following reasons for never having accessed professional assistance: illness or injury of family member that required immediate nursing facility placement (36.4 percent; n=4); family member refused home care (36.4 percent; n=4); didn't know home care was available (27.3 percent; n=3); didn't want strangers in the house (27.3 percent; n=3); and home care was too expensive (27.3 percent; n=3).

The survey asked respondents about whether they had experienced specific problems with their professional home care. Table 3 indicates the number of respondents who found certain conditions to be problematic in their experience utilizing formal home care. The problem reported by the most respondents; "workers changed often, so I never knew who was coming", may reflect the current tight labor market and the inability of home care agencies to maintain employees. The other problems experienced by respondents included; 1.Workers didn't stay long enough. 2. Arrival times were inconsistent. 3. Workers didn't show up on time. These problems could also be related to a labor market in which the demand for home care is greater than the supply

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of workers; this results in a small number of home care workers carrying large caseloads, not having enough time for each client, and falling behind schedule.

Training

A final section of the survey asked respondents about training they had received or would have liked to receive to help them in their caregiving work. Only nine respondents (23.7 percent) had received training or written information on providing care to their loved one during their months of caregiving. Over two thirds of the respondents (67.6 percent; n=25) wished they had received more information to help them with their caregiving role. Specifically these caregivers said they would have liked more training about how to prevent difficult behavior (n=15; 60 percent); training in how to communicate with the care receiver (n=13; 52 percent); training in caregiving activities—i.e., bathing, lifting—(n=13; 52 percent); and training about issues with other family members (n=12; 48 percent). Additional training topics that individual respondents said would be helpful included: training in how to find respite care; training in preparing for the future—e.g., living wills; and training in how to obtain good home care workers.

Urban/Rural Comparisons

Given the small size of the sample, subgroup comparisons must be done with caution. Nonetheless, an examination of how the caregiving experience for the more rural caregivers differs from their counterparts in larger towns may shed light on some of the particular circumstances and challenges of rural aging. The four caregivers that were not living in Maine were not included in this analysis. Rural caregivers were more likely to be female (88.0 percent vs. 63.6 percent, p=0.09) and more likely to care for other dependent adults (20 percent vs. none, p=0.11). Rural respondents had received less formal education than urban respondents had; all six respondents in the sample who had not finished high school lived in rural areas.

The cost of home care appeared to be particularly prohibitive for rural respondents who cited it more frequently as an important reason for moving their loved one to a nursing facility (64 percent vs. 9.1 percent, p<0.05). Similarly, on average, urban respondents had been providing care to their loved ones at home for a significantly longer period of time than rural respondents (91.7 months vs. 33.0 months, p<0.05) before nursing home placement.

Rural respondents appeared to be particularly hungry for more information to help them in their caregiving. While less than half of the urban respondents said they would have liked more training (45.5 percent; n=5), over three-quarters of the rural respondents (76.2 percent; n=16) said they were interested (p=0.08). Interestingly, while rural respondents seemed most interested in learning more about preventing difficult behavior (60.0 percent vs. 20.0 percent, p=0.11), communicating with the care receiver (50 percent vs. 20 percent, p=0.23), and particular caregiving activities (50 percent vs. 20 percent, p=0.23), urban respondents were more interested in learning skills to deal with issues with other family members (80 percent vs. 30 percent, p<0.05).

Discussion

In 1994, after 20 years of relying almost exclusively on nursing homes as the way to deliver long-term care services, Maine's legislature put forward a package of reforms, supported by elder and disabled advocates, which offered consumers more home and community care options and reduced reliance on nursing facilities. From 1995 to 1998, state and Medicaid expenditures shifted dramatically, with a 22 percent decrease in spending for nursing facilities and a 74 percent increase in spending for home care (Maine Department of Human Services, 1999). In order to continue this positive trend toward community based care, it will be important to understand the needs of family caregivers, and to monitor the adequacy of home based care. This study provides a preliminary exploration of the intersection of family caregiving and professional home care in a rural state.

The results of this survey substantiated the existing anecdotal evidence that inadequacy and

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TABLE 3:
Problems Experienced with Professional Home Care

Problem	Nurses (n=21)	Other Home Care (n=27)
1. Workers changed often so I never knew who was coming	7 (33.3%)	11 (40.7%)
2. Workers didn't stay long enough	4 (19.0%)	9 (33.3%)
3. I never knew what time of day the worker would arrive	4 (19.0%)	5 (18.5%)
4. Workers didn't do what I wanted	3 (14.3%)	5 (18.5%)
5. Workers didn't show up on time	2 (9.5%)	6 (22.2%)

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unreliability of professional home care services may, at times, contribute to decisions by families to stop providing care for their loved ones at home. The cost of home care was a particular concern for rural caregivers. This may be because of lower incomes in rural areas (though such income disparity was not evident in this particular sample of caregivers) or the higher cost for home care in more geographically isolated parts of the state. Urban respondents had been able to provide their loved ones care in their homes for a statistically longer period of time before nursing facility placement, perhaps because of greater accessibility to home care services. The specific problems experienced with professional home care by both urban and rural respondents reflect a need for more hours of home care, more consistency in workers and more control over the time that the worker arrives. Increasing the supply of home care nurses and PCAs might alleviate some of these problems. Making wages and benefit packages more competitive for this predominantly female employment could well ease some of the current staff shortages. At current wages, individuals raising families would be unable to make ends meet with the wages from home care employment alone.

Perhaps reflecting their geographic isolation, rural respondents were more likely to say they would have liked more information to help them in their caregiving role, though nearly half the urban respondents also said such information would have been helpful. While rural respondents seemed most interested in learning specific skills to assist them in communicating with and helping their loved ones, urban respondents were particularly interested in learning skills to deal with issues with other family members. It is unclear why extended family concerns are more important to urban respondents than rural respondents. While it is tempting to hypothesize that rural families have fewer family feuds and are more likely to share the responsibilities of caregiving, prior research does not bear this out.

Clearly some families, particularly in rural areas, need more financial assistance in paying for home care. In this sample, rural respondents were less educated, more likely to be female and more likely to be caring for other dependent adults; these individuals appear to be facing the double jeopardy described by Krout and Coward (1998). The recent amendment to the Older Americans Act, creating the National Family Caregiver Support Program, will provide new funding to Maine ($564,300 in 2001) to increase services to family caregivers. The development of this program symbolizes national support for the many family caregivers who provide so much of the nation's long-term care, and the recent funding allocated to Maine will be useful in supporting and augmenting the state's current efforts to meet the needs of family caregivers. Nonetheless, based on the results of this study, this new funding represents a very small step toward what should be our long-term national goal of more adequately supporting and valuing the work that both professional and family caregivers provide for our frail elderly in urban and rural areas alike.

This study adds to what we already know about caring for frail elders in rural settings and has implications for geriatric care management practice. Prior research identifies particular challenges care managers can expect to face when working with rural elders and their families. These include higher poverty rates and higher rates of illness and disability. Additionally, it has been well documented that rural areas have less accessible and fewer health and human services; this study provides further evidence of that situation. The relative lack of continuum of care services and the difficulty in recruiting professionals are also particular concerns for geriatric care managers in rural settings. Moreover, family caregivers in rural settings are frequently more isolated and receive less help with their caring work than do caregivers in urban areas. Fear, lack of knowledge, high expense and dissatisfaction with home care personnel may all contribute to rural elders and their families not receiving the professional home care they need. This is compounded by the dearth of home care workers in a tight labor market. Also of importance for geriatric care management, is the interest rural caregivers expressed in this study for further training and information so that they could better care for and understand the needs of their loved ones.

In Maine, recent policy decisions have reduced the number of geriatric care managers throughout the state. It appears that families in this study, urban and rural alike, may have been negatively affected by this change and could benefit from more help in navigating the system and getting the assistance they need. There is the risk that rural elders and their families in particular will be further isolated when the work of geriatric care managers is not supported at the policy level.

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Family Relations and Networks Among Rural Elders: Implications for Geriatric Care Management

By Lorraine Dorfman, Ph.D.

Introduction

The vast majority of care of frail elders in this country is provided by informal social networks, particularly by close family members. This may be even more the case in rural environments due to both cultural preferences and lack of availability of formal health and human services. The challenge for geriatric care managers who work with rural families is to understand what is known about the dynamics of rural family life, how the family system responds to the need for care of frail elders and how best to interface between these informal care providers and the formal system of care.

The purpose of this article is to present information on rural family relations and networks and to provide suggestions for geriatric care managers who work with frail rural elders and their families. The article will first provide background on how rural environments can be expected to impact family life. It will then examine myths and realities concerning rural family life, and go on to examine the patterns of formal service use that may complement care provided by rural families. Finally, it will provide suggestions for geriatric care managers who work with families in rural settings.

Impact of Rural Environments on Family Life

Social and Demographic Trends

Approximately one of every four elders lives in rural areas, the great majority in small towns and villages and the remainder on farms or in open country. Both the aging process and family life are affected by this rural context. One important issue facing families in many rural communities is geographic distance from needed goods and services. Some rural communities may simply have too small a population to develop and support the health and human service infrastructure that larger communities can provide (Coward, McLaughlin, Duncan & Bull, 1994), necessitating travel to metropolitan areas for services, which in turn places an added burden of transportation on rural families.

A second important issue affecting rural families is the out-migration of the young to urban areas in search of educational and employment opportunities. The depopulation of small towns and the countryside can have serious consequences for aging family members who are left behind. In Iowa, for example, which suffered more out-migration than any other state other than West Virginia in the 1980s (Elder, Rudkin, & Conger, 1994), there is currently a serious labor shortage and a burgeoning population of people over age 75. The depopulation of the countryside may in part be attributed to the increase in large-scale corporate farming in agricultural states. Along with less geographical proximity and probable reduction in contact between generations caused by outmigration from rural areas, there are several other general societal trends that have impacted rural as well

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as nonrural families in recent decades: low birth rates, high divorce rates, the changing status of women that results in more women working outside the home and subsequent realignment of family roles and responsibilities. All of these factors affect availability of family care for rural elders.

Economic Status of Rural Elders

Rural elders on the average are economically disadvantaged relative to their nonrural counterparts. There is a long-term picture of lower earnings and higher poverty rates among rural vs. nonrural elders; this limits their ability to purchase long-term care services (Dorfman, 1998; Krout & Coward, 1998). Lack of financial resources puts a particular burden on informal care providers, particularly families to provide care. One explanation for the residential difference in economic status of rural and nonrural elders is structural; that is, the types of jobs in rural areas tend to be low technology, labor intensive, low wage and considerably affected by swings in the national economy. At particular risk for economic insufficiency in rural areas are the very old (who are also often frail), women and racial and ethnic minorities. Minority status may interact with a tendency to underutilize public assistance that is common among rural dwellers, creating a severely economically disadvantaged group (McCullough, 1996).

Health Status of Rural Elders

Rural elders are at risk for poor health and disability for a number of reasons: low income, lack of transportation, geographic isolation and lack of access to formal services. Some researchers have found that rural elders have more functional health limitations and a greater number of medical conditions than do nonrural elders. Rural non-farm elders, who comprise the bulk of rural elders, have the worst health status of any nonmetropolitan or metropolitan residential category. They have more medical conditions, more functional limitations and more problems in performing activities of daily living and instrumental activities of daily living than any other residential group (Coward et al., 1994).

Diversity in Rural Environments

Rural environments are very diverse, yet the myth persists that rural elders are all pretty much alike and live in similar environments. Great diversity exists with regard to population density, farm vs. nonfarm residence, type of occupation, ethnic makeup, regional culture and awareness of and access to services (Krout & Coward, 1998). These factors interact in complex ways, so that the life situation of an African-American elder in rural Mississippi may be quite different from that of a Hispanic elder in rural Texas or a white elder living in a small village in upstate New York. What most rural elders do have in common is that they suffer the "Double Jeopardy" of age coupled with residence in often remote, sparsely settled areas lacking sufficient resources and services.

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Myths and Realities of Rural Family Life and Networks

The popular image of rural family life is of a family of multiple generations living in close residential proximity and characterized by close affectional ties and a great deal of mutual support and assistance. Part of this image rests on the belief that traditional family values in rural settings help foster larger and stronger family networks than in nonrural settings (McCulloch, 1996; Stoller, 1998). The reality revealed by empirical studies is far more diverse and complex than this idyllic picture of rural family life and generally shows that rural elders do not have more proximate kin, higher interaction levels or receive more assistance from kin than do nonrural elders. The two major sources of support for rural elders are the spouse, if married, and adult children.

Marital Relations

A higher proportion of rural elders, particularly farm elders, are married than are nonrural elders, perhaps because rural elders tend to be somewhat younger and thus are not yet widowed and also because they are less likely to be divorced than are their nonrural counterparts. Rural marriages appear to be more stable than those in other residential settings (Stoller, 1998), with the spouse being available to provide needed assistance when the other spouse falls ill. This picture of rural marital advantage, however, masks some problems that marital partners in

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rural areas face. For one thing, rural spouses, especially wives, may be caring for their partner without adequate financial resources and available services, often with detrimental effects to their own health (McCulloch, 1996). For another, the marital advantage tends to disappear among very old rural elders, aged 85 and above, leaving them without a spouse and with the need for assistance when in poor health. Finally, the experience of widowhood, when it does occur, may be different in rural than in nonrural settings because of the prevalence of traditional gender values and roles. For instance, older rural women may not know how to drive, which hampers their mobility, and older rural men may not know how to perform traditional female tasks such as cooking and cleaning (Stoller, 1998). Consequently, new roles have to be learned in order to deal with daily essentials such as transportation and self-care.

Little is known about non-married rural elders, who are a very heterogeneous group including the never-married, divorced or separated, widowed, and gays and lesbians. One group of particular concern is male farm laborers who are often lifelong singles. Who provides care for them as they grow older and more frail? Likewise, little is known about gay and lesbian elders in rural communities. We do know that gays and lesbians are less likely to live in rural than in urban settings, perhaps because rural people are generally not very supportive of homosexual relationships (Stoller, 1998). But the question remains: Who provides support for aging gays and lesbians who continue to live in rural communities when they become old and need care?

Relations With Adult Children

Although rural elders are more likely to have children and to have a larger number of children than nonrural elders, it does not follow that they receive more support and assistance from them (Stoller, 1998). Powers & Kivett (1992) found that children were the major caregivers of rural elders, but that weekly assistance was provided by only about one-third of children. Expectations for kin assistance were much higher than actual level of support given by children and other kin in that study. One important reason is outmigration of grown children from rural areas, which means there are fewer geographically proximate siblings to care for their aging parents. Extended kin, such as siblings and nieces and nephews, become more important among rural elders without proximate children (Stoller, 1998). Interestingly, farm parents are advantaged over nonfarm parents in terms of proximate children, because a son is often involved in the farm and lives nearby or even co-resides with aging parents.

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There are several other things to consider when assessing support available for rural elders from grown children. One factor is that a significant minority of rural elders have never had children or have no living children or grandchildren available to help (Dorfman & Mertens, 1990; Stoller, 1998). Another factor is that even elders with proximate children and grandchildren are not guaranteed affection and support from them, because it is the long-term quality of intergenerational relationships, not just proximity and availability, that helps determine patterns of care of the elderly.

Farm/Nonfarm Differences

Although farmers are a decreasing proportion of rural elders, their lifestyles and life histories are often quite different from those of other rural-dwelling elders and thus merit attention. Work and family life tend to be intertwined on the farm; consequently, work and family roles are less likely to be seen as separate than in nonfarm families (McCulloch, 1996). Farming often involves parents and their grown children, so that more than one generation may work the family farm. Farm wives are usually integral to the farm enterprise and are often involved in the day-to-day operation of the farm and in important decisions about the farm.

An important point about farm families is that women play a particularly prominent role in care of parents and parents-in-law when they are ill (Elder et al., 1994). This may be due in part to geographic isolation of many farms and inability of surrounding communities to offer needed services, but may also reflect rural values of independence and self-reliance. Farming is one of the most dangerous occupations; thus, farm-related accidents and illnesses may increase the need for family care. Farm injuries and illnesses can also cause financial problems, resulting in the need for more home care provided by farm families, usually women (McCulloch, 1996).

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Older Rural Men: An Often Overlooked Population

Much more attention has been given to the situation of older women than older men. Older men in general tend to have less extensive social networks than do older women, and unless married, are less likely to have a confidant than are women. Older rural men may be disadvantaged in terms of frequency of contact and aid received from family members. Dorfman and Mertens (1990) found considerable gender differences among older rural men and women in amount of aid received from both children and siblings, with men receiving less help on occasions like illness and in transportation. Furthermore, widowhood may be particularly hard on rural men, not only because of adherence to traditional gender roles and loss of the possibly health-promoting behaviors of their wives, but because they are less likely to move to metropolitan settings with greater service availability after being widowed than are women (McDonald, Quandt, Arcury, Bell & Vitolins, 2000). Older widowed rural men, particularly farm men, may be at risk of isolation after their wives die.

Rural Family Network and Formal Services

Families, assisted by networks of friends and neighbors, are more likely to be the main, and often the only, source of support for rural elders than they are for nonrural elders. In addition, more rural families are frequently caring for sicker and more impaired elders than are nonrural families because of the paucity of services and public transportation in many rural communities. Where family caregivers are not available to provide assistance, traditional "neighboring" in the form of help from friends and neighbors may help compensate for lack of kin (Stoller, 1998; Stoller & Lee, 1994). Some of the same conditions, however, that may hinder family members from being available to help an impaired elder, may also reduce the help that friends can offer: geographic distance, lack of transportation, poor roads, and in many parts of the country, severe weather conditions. Rural families turn to formal services for assistance when kin and non-kin networks cannot handle caregiving tasks alone, when specialized care services are needed or when the condition of the elder is grave.

Services and Service Delivery in Rural Areas

There is a clear rural disadvantage in service availability, accessibility and delivery in many rural communities in the United States, which becomes an even greater concern when we consider that rural dwellers are disadvantaged with respect to health, income and housing. In most rural communities, there are fewer hospitals, other health services and trained health and human service providers available than in nonrural communities (Coward et al., 1994; Krout, 1998). The rural disadvantage extends across the continuum of care, from home and community-based services to institutional services, particularly hospitals. The many hospital closures in rural areas have occurred because those hospitals are not able to survive economically, and other hospitals have remained open only by reducing their range of services (Krout, 1998). All of these factors place an extra burden of care on rural families.

With respect to in-home services, there are fewer home health agencies available to assist families by providing home health aides and homemakers in rural than in nonrural areas. It is also often more costly to deliver in-home services such as meals on wheels to rural-dwelling elders in sparsely settled or isolated rural areas, and it takes more time to deliver those services. In a study of access to home health care services, Kenney (1993) found that urban Medicare home health use rates were 9.1% higher than rural use rates, even when supply and demand conditions were similar. She concluded that access to home health services in rural areas is limited by lower Medicare reimbursement ceilings, proportionately fewer visiting nurse associations, and less availability of auxiliary services such as physical therapy and medical and social services than in urban areas. Community-based services for rural elders suffer some of the same problems as do in-home services: lack of population density to sustain services, geographic distance which makes services costly and time-consuming to deliver, fewer services available than in urban areas, gaps in the continuum of care, and uneven provision of services.

A particular source of support for elders and families in rural areas is the Area Agencies on Aging (AAAs). The AAAs provide almost twice as many services directly to rural elders and their families as they do in nonrural areas, as well as providing information and referral services, planning, advocacy, and coordination of services (Krout, 1998).

The Institutional Alternative: Rural Nursing Homes

Given the relative dearth of home and community-based services in many rural communities and gaps in the continuum of care, it is not surprising that many rural families are forced to place their frail elders in nursing homes. This is particularly the case for widowed, divorced and never-married rural elders, since absence of a spouse in the home is associated with institutionalization. Forty percent of all Medicare-certified nursing homes are found in rural settings, although only about one-fourth of elders reside in those settings (Coward, Duncan & Uttaro, 1996). Rural areas not only have a disproportionate share of nursing homes, but many nursing homes are smaller and have fewer beds than in nonrural areas. Rural nursing homes are less likely than nonrural nursing homes to be able to return their patients to home settings because of the lack of supportive services available to help families care

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for their frail elders. This may result in problems in being able to admit new elderly patients in need of care to rural nursing homes (Coward et al., 1996), further increasing the demands for care on families.

Implications and Suggestions for Geriatric Care Managers

The challenge for geriatric care managers in rural settings, including nurses, social workers and other allied health professionals, is how to best support families in their efforts to care for their frail elders and to connect them to local and nonlocal services as needed. The following are suggestions for care managers who work with elders and their families in rural environments.

Be Sensitive to Rural Attitudes and Values. Practitioners in rural settings need to be aware of and responsive to the attitudes and values of rural people, which generally reflect a strong ethos of independence, self-reliance and responsibility. These values were formed growing up in ecological settings that stress individualism and dependence on close family members rather than reliance on the service bureaucracy and government programs. Care managers need to understand and respect these values and at the same time be able to address negative attitudes about service use. Care managers can help rural families reframe negative feelings about asking for outside help, and assist in preparing families for the time when they are not able to cope with the demands of caring for their frail elder without outside help, hopefully before a crisis in care occurs.

Be Aware of the Diversity of Rural Populations and Design Programs to Meet Diverse Needs. It is important for practitioners to recognize and be responsive to the heterogeneity of rural elders and their families because there is considerable variation among rural dwellers based on regional and cultural differences, ethnicity, farm versus nonfarm residence and family structure. The supports and care needed by older rural migrant workers who follow the crops, for example, are quite different from those of older people who are long-time established community residents with an informal network of family and friends to rely on. There may be considerable differences among rural ethnic and racial minority subpopulations with regard to attitudes about reliance on informal supports and acceptability of outside services. It is important for care managers to offer and evaluate services and programs with this heterogeneity in mind. It is also important to develop and offer services that are not based on the dominant urban model, which is often inappropriate for rural populations.

Train Family Caregivers in Basic Caregiving and Nursing Skills Increasingly, family caregivers are being called upon to provide health care services, such as monitoring and administering oral and intravenous medications and handling appliances, in addition to providing personal care such as help in bathing and feeding. Care managers can help train rural caregiving families in basic health and caregiving skills. Educational programs should be developed to inform rural caregivers about basic caregiving skills and to help promote wellness. Such programs should be offered in convenient community meeting places such as senior centers, churches, and community centers. Care managers can also arrange for dissemination of written materials and videotapes, as well as use the media, to provide information about health and health care resources that will assist caregiving families. Working through existing networks in rural areas, such as the Cooperative Extension Service, may be particularly useful in reaching families in scattered or isolated geographic locations.

Provide Respite Care for Family Caregivers. It is crucial to provide periodic respite for family caregivers in order to avoid excessive fatigue and burnout. Time out from caregiving can help maintain caregiver health so that there are not two patients instead of one, and may also result in better health care for the frail elder. Facilitating time-outs for caregivers to regroup and conserve their energy is particularly important in rural settings because of the heavy reliance on family care. Practitioners can help relieve family caregivers by identifying and marshalling friends and neighbors who might be able to help. They can also advocate for policies that would provide reimbursement for community volunteers who can be utilized to provide respite for family caregivers.

Seek Out Community Supports for Isolated Elders. Care managers can build on the strengths and resources of rural communities in helping to care for frail elders in general, and particularly those elders who are most at risk because their families are too far distant or who have no family members available to help. Of particular concern are unmarried and childless elders and gay and lesbian elders, who may be stigmatized by the rural community. Local organizations such as churches, 4-H and community centers may be able to offer surrogates for family help to those vulnerable elders. Because churches play a prominent role in many rural communities and for some rural subpopulations such as African-Americans, it makes sense for care managers to work with local churches in helping to arrange visits and care for rural elders who do not have kin available to help. Practitioners can also build on local community resources by identifying gatekeepers such as mail carriers and shopkeepers who can check up on frail elders who live alone, and recruit local volunteers to provide needed transportation.

Advocate for Training of More Professionals In Rural Areas. A serious shortage of trained professionals exists in many rural communities due to outmigration, geographic distance from metropolitan areas, and perceived lack of chances for advancement and cultural opportunities. Shortages of physicians, nurses, all

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kinds of therapists, social workers and other allied health professionals exist. Care managers who are already practicing in rural environments are often overburdened and painfully aware of the shortfall of trained professionals, and need to advocate with local and state leaders for more training and educational opportunities for practitioners that are tailored to the needs and values of rural dwellers. Education and training opportunities should include continuing education for providers who are already working in rural settings; this will likely take the form of distance education. Advocacy also needs to stress improved compensation for rural practitioners, whose salaries usually lag behind those of their urban counterparts, in order to help attract them to rural settings.

Improve Coordination of Informal and Formal Care. Care managers can try to create better linkages and partnerships between natural helpers and in-home and community based services in rural communities. Both informal and formal care systems are often fragmented, which can be particularly problematical in rural areas because of distances involved. Coordination of care may best be achieved through implementation of case management services. One recently developed model is the "Models Project" in Ontario, Canada, which provides assessment and care for elders in a widespread rural area of the province (Harris, Crilly, Stolee & Ellett, 1999). In this project, interdisciplinary teams were trained to serve as local resources in geriatric assessment and intervention, and local community support and collaboration were solicited and received.

Conclusion

Despite out-migration and economic restructuring in many rural communities, informal family care remains the first, longest and most preferred form of eldercare for most rural elders. When older persons become so ill that outside services are needed, rural families generally accept and may facilitate access to the formal health and human service system. Outside services are likely to be utilized to the extent that they reflect rural values of independence and control, and to the extent that they are available and accessible. Geriatric care managers must be mindful of these realities if they are to implement interventions that will be helpful for rural elders and their families.

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A Guide to Resources for Rural Care Managers

By Linda J. Redford, Ph.D., R.N. and Steve Corbett, M.A.

Rural care managers must be the proverbial "Jack of All Trades" and able to contend with a complex puzzle of needs and deficits in resources to meet the needs. Demographic, social and economic conditions in rural communities combine to magnify resource needs and deficiencies. At the same time, the demand for service resources in rural areas often far exceeds that of urban communities. From a quarter to a third of the population in many rural communities are 65 years-of-age or older, with a significant percent being very elderly and at high risk of needing multiple long-term care services. The rural environment of economic decline with an eroding base of monetary and human resources poses challenges to the creativity and resourcefulness of the most seasoned care manager.

Despite the complexity of their jobs, few rural care managers receive formal training for their roles. While some large, urban-based care management programs provide in-service training and mentoring opportunities for new care managers, this is a rarity in rural areas. Those who assume care management positions in rural communities often have little opportunity for formal training; the rural care manager must be a self-directed learner.

This article provides rural care managers information and strategies for attaining information that will assist them in meeting the daily demands of their role. Reference books, instructional texts, journals and electronic resources are reviewed. Emphasis is given to the Internet both for seeking and obtaining resources. Given the isolation and less than optimal access to information that rural care managers encounter, the Internet is one of the most powerful tools available and one that is becoming increasingly vital for those in rural and remote areas.

Books, Manuals and Journals

For novice care managers, it is important to have an understanding of the history and basic principles of care management. There are some classic books that provide overviews of community-based care management. They provide the philosophy, processes, practical advice and examples that have withstood the test of time and may assist care managers in performing their roles more effectively.

The History, Philosophy and Practice of Care Management

***Case Management and the Elderly* by Raymond Steinberg and Genevieve Carter, Lexington, MA: Lexington Books, 1983.** This book is truly a classic in the community-based care management field. It provides interesting reading for the novice care manager seeking to understand the foundations of care management. This book is no longer in print, but can be found in some libraries or through interlibrary loan. It may also be possible to purchase copies over the Internet through *www.amazon.com*.

***Successful Case Management in Long-Term Care* by Joan Quinn, New York: Springer Publishing, 1993** (*www.amazon.com*). Written by the director of one of the oldest care management programs in the country, this book is also good for those entering the field of care management. It provides a succinct and interesting overview of the history of care management, the basic processes of care management, and approaches to common issues and dilemmas care managers frequently confront.

***Long-Term Care Case Management: Design and Evaluation* by Robert Applebaum and Carol Austin, New York: Springer Publishing, 1990** *(www.springerjournals.com/store/catgglc.html.)* The authors bring their extensive experience in the development and evaluation of community-based care management programs to this work. They provide a synthesis of information on the design of programs and strategies for evaluating and ensuring quality in care management programs.

***The Practice of Case Management* by David Moxley, Newbury Park, CA: SAGE Publications, 1989** (*http://www.amazon.com*). Moxley includes a very good chapter on assessment of social support systems and approaches to building responsive social networks. He also provides some useful tools and approaches for monitoring care and evaluating the care management process.

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Building Programs and Conducting Care Management

The rural care manager is often responsible for the care management program. There are a number of books that provide rural care managers guidance in programmatic development and management, as well as in the process of working as a care manager.

Handbook of Geriatric Care Management **by Cathy Cress, Gaithersburg, MD: Aspen Publishers, 2001** *(http://www.aspenpublishers.com).* This is one of the newer books on the market and one that specifically addresses geriatric care management. Critical issues in care management, such as ethics, quality and decision-making, are addressed. This book also provides useful examples of tools, forms and sample letters needed in care management programs.

Fundamentals of Case Management Practice: Exercises and Readings **by Nancy Summers, Belmont, CA: Wadsworth Publishing Co., 2000** (*http://www.wadsworth.com).*

Although this workbook is intended for classroom situations, it can be used as a self-study tool. It covers the basics of care management and provides vignettes that illustrate the ethical issues that arise in care management. Issues relating to cultural diversity are provided, as are practical examples of other common scenarios and "how-to" tips. Forms for record keeping and service planning are included.

National Association of Professional Geriatric Care Managers *(http://www. caremanager.org/gcm/ProfCareManagers.htm*). This website has a "store" where care managers can purchase hardcopy professional development materials that will assist them in their care management practice.

Practice of Generalist Case Management **by Barbara Holt, Needham Heights, MA: Allyn & Bacon Publishers, 1999** (*http://www.ablongman.com*). This is a practical and basic introduction to care management. It provides case examples to illustrate and reinforce points. Designed for entry-level students, this is a very good reference for the beginning care manager.

Case Management: Integrating Individual and Community Practice **by Jack Rothman and Jon Sager, Needham Heights, MA: Allyn & Bacon Publishers, 1998** (*http://www.ablongman.com*). This book provides information on both the theory and design of care management programs. These authors integrate the theory and practice of care management to provide a practical reference for developing a care management program.

Case Management by Design: Reflections on Principal and Practices **by David Moxley, Wadsworth Publishing, 1997** (*http://www.wadsworth.com).* Moxley provides an overview of the models of social work care management and the purpose of care management in today's human service systems. This is a practice-oriented text with many practical suggestions of ways to overcome the issues and barriers care managers may confront in community practice.

The more recent books on care management tend to focus on disease management and managed health care. Although managed care has been slower to penetrate rural areas, rural care managers are increasingly required to interface with managed care organizations. In today's environment, it is imperative that even care managers who work in the social and supportive human services arena understand the function of the care manager in managed care. The following are some books that provide comprehensive reviews of the care management philosophy and process in managed care:

The Case Manager's Handbook **by Catherine Mullahy, Gaithersburg, MD: Aspen Publishers, Inc 1998** (*http://www.aspenpublishers.com).* Mullahy provides a very comprehensive discussion of the roles of the care manager in insurance and managed care systems. Many of the strategies suggested and forms provided can easily be incorporated in other care management environments. There are also chapters on home care and long-term care that incorporate information useful to geriatric care managers.

Case Management: A Practical Guide to Success in Managed Care by Suzanne Powell, Baltimore, MD: Lippencott Williams & Wilkins, 2000 (*http://www*.lippincott.com). This text provides an excellent overview of information about insurance coverage for various service levels, regulatory issues, service options and the criteria for eligibility, quality reviews and much more.

Assessment

A comprehensive assessment is the foundation of the care management process. Valid and reliable tools are critical to measuring improvement or deterioration in a client's condition or abilities and accurately evaluating the effectiveness of interventions. Many care management texts emphasize the importance of comprehensive and standardized assessment, but few provide specific recommendations regarding tools or instruments to guide this process. The following are resources that provide specific tools and approaches to the assessment process.

Comprehensive Geriatric Assessment **edited by Dan Osterweil, Kenneth Brummel-Smith, and John Beck, New York: McGraw-Hill, Medical Publishing Division, 2000** (*http://www.bookstore.mcgraw-hill.com*)**.** Although targeted to physicians, this text contains many examples of standardized assessment tools and approaches in geriatrics that can easily be used by other professionals.

Assessing the Elderly: Measures, Meaning, and Practical Applications, **edited by Rosalie Kane and Robert Kane with the assistance of Marilyn Eells, New York: Oxford**

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University Press (*http://www.oup-usa.org/index.html*). This book is an update and expansion of the Kanes' text on assessment tools written in the early 1980s. It provides a comprehensive coverage of the tools and strategies for assessing functional, physiological, emotional, cognitive, social, and spiritual preferences of individuals, as well as their social and physical environment. A chapter on assessment of elders who cannot communicate is particularly relevant.

***Measurement in Elderly Chronic Care Populations* edited by Jeanne Teresi, M. Powell Lawton, Douglas Holmes and Marcia Ory, New York: Springer Publishing, 1997** (*http://www.springerpub.com).* This book provides a comprehensive examination of measurement tools and strategies that are appropriate in use with older persons who require chronic care. Each chapter covers a specific aspect of assessment ranging from functional, cognitive, emotional and sensory assessment to environmental assessment.

Journals are helpful in keeping up-to-date on new trends and issues in care management. The following are journals devoted primarily to community-based care management issues.

The ***Geriatric Care Management Journal*** (*http://www.caremanager.org)* is a publication of the National Association of Professional Geriatric Care Managers and offers care managers a variety of articles relevant to the practice of care management with older adults. The merger of the Journal of Case Management and the Journal of Long Term Home Health Care created the ***Care Management Journals*** *(http://www.springerpub.com)*. The result is a journal that covers a wide spectrum of care management issues across all long-term care populations as well as issues relevant to health care in the home for chronic conditions.

Keeping Current and Connected Through Technology

The Internet provides a computer savvy care manager almost any type of information needed to plan and deliver care to older adults and to function effectively as a care manager. The most current and cutting-edge information on all aspects of funding and reimbursement, regulatory guidelines and service availability is available via the Internet. Although Internet access is more problematic in rural areas, rural providers are rapidly moving into the cyberspace era. It is rapidly becoming a primary resource for information in all areas and one that care managers must become proficient in using to practice effectively and efficiently in today's human services environment.

The wealth of information available via the Internet is its greatest strength, but also its greatest drawback. For the novice user, searching for information on the Internet may be time-consuming and potentially frustrating. Still, taking the time to look for information and experimenting with various search engines, such as Yahoo, Excite, Netscape, Hotbot, Lycos and others, is a necessary step in understanding and gaining full benefit from the Internet.

Search engines are highly variable in effectiveness, depending on the specific topic being researched. Users may also find they have preferences about how information is displayed or categorized by the various search engines. It is instructive to experiment with searching by different words and word groupings to determine which best target areas of interest.

Once sites are identified, the next problem becomes evaluating the accuracy of information. It is best to rely on reputable and trusted sites. It is also important to look for sites that display the latest date on which the site was updated. For information on health conditions, recent research, demographic information or evaluation of products or services, sites with ".edu", ".org", and ".gov" in the URL tend to be the most reliable. The ".com" sites are useful for finding products and services, but it is best to use companies with a known track record. The Internet is rampant with scam artists.

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Information on Funding for Health and Long-Term Care, Policies, and Regulations

Care managers must have a thorough knowledge of funding streams for services, eligibility requirements, and appropriate methods for securing available service options. The following is a listing of websites that will familiarize care managers with the various programs and keep them abreast of current policy, service and regulatory changes.

The Centers for Medicare & Medicaid (CMS) formerly Health Care Financing Administration (*http://www.hcfa.gov)* website provides information on Medicare and Medicaid ranging from fairly simplistic information on benefits and coverage for consumers to highly technical data and regulatory information for providers, researchers, state agency personnel and analysts. This site also provides links to state Medicaid agencies.

The *Administration on Aging*

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(*http://www.aoa.gov/default.htm*) website provides information on governmental programs designed to assist elderly Americans, as well as information on the laws and acts designed to serve and protect aging individuals in the U.S. Included on the site are links to state and regional organizations that provide services to elders and their caregivers and links to sites housing information and education on elder issues.

The *Veterans Administration* (*http://www.va.gov)* serves the acute and long-term care needs of many veterans. The VA website provides information on all VA services, including long-term care services. Eligibility for VA benefits is covered and information is provided on the location of VA facilities and service centers.

The *Indian Health Services* **(** *http://www.ihs.gov)* serves 550 federally recognized tribes in the U.S. Most of their members live on reservations and in rural communities in 34 states. The IHS does not fund long-term care services, but provides a bulk of the healthcare for Indians. This website provides information on the services available through IHS, including a small section on an Eldercare Initiative.

A site that provides links to the sites noted above and to many other resources on policies and laws relating to health care and long-term care is *Health Hippo (http://hippo.findlaw.com).* This site has resources specific to rural health issues and is very user friendly.

Finding Services and Needed Products

A major role of care managers is to assist their clients in obtaining the services, products, assistive devices and support they need. For the rural care manager, knowledge of local service options may be a relatively simple task. It becomes far more complex when needed services or products are not available locally.

Telephone books, product catalogs, state and local service directories, and marketing materials have long been necessities in the care manager's arsenal of resources. Today, the Internet puts the most current and comprehensive information on all types of services and products at the care manager's fingertips.

Most state departments responsible for coordinating federal and state funded services have websites that provide links to local providers. State departments can be located by searching for the department by name and state. Alternatively, websites of the Administration on Aging (*http://www.aoa.gov*) and the Centers for Medicare & Medicaid (CMS) (*http://www.hcfa.gov*) provide links to state sites.

Links to state, federal and local agencies can also be found in the *Case Management Resource Guide (http://www.cmrg.com).* This guide is a comprehensive online directory of healthcare, homecare, and other services throughout the country. Hard copies are also available.

Many communities, even some small communities, have their own websites that can be found by searching on the name of the town and state. These websites frequently provide information about medical, housing and social services available in the community and sometimes links to provider and agency websites.

Telephone books for communities in the United States and throughout the world are also available on the web. Among the more comprehensive and user friendly sites are: Switchboard *(http://www.switchboard.com)* and Super Pages *(http://www.superpages.com).*

Assistive Devices and Home Modifications

Finding and procuring assistive devices and/or home modifications that allow disabled elders to function more independently is an important aspect of care management. In rural areas, adaptive equipment may not be readily available and the care manager may be required to seek equipment and services elsewhere. Again, the Internet is an important resource.

The website of the Center for Assistive Technology at SUNY-Buffalo (*http://wings.buffalo.edu/ot/cat)* presents the research, education, services, and products available from the Center. Of particular value is the Cornucopia Of Disability Information Page that contains information and links to sites on everything from the definition of assistive technologies to getting the desired products.

ABLEDATA (http://www.abledata.com/index.htm*)* is sponsored by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. This site provides information on assistive devices and accessible housing, links to product manufacturers, a site where consumers can provide product evaluations, and links to disability resource centers, including some specific to certain disabilities.

The *National Council on Disability (http://www.ncd.gov)* site is a useful resource on policy issues relating to disability and provides links to federal agencies that play a role in serving or protecting the rights of the disabled.

Housing Options

There are times when in-home services, home modifications, and assistive devices are not enough to allow a person to remain in their own home. It then becomes the role of the care manager to assist that person in identifying available housing options.

The American Association of Homes and Services for the Aging (AAHSA), *(http://www.aahsa.org)*, represents the not-for-profit nursing facility sector and many assisted living facilities in the U.S. A search function available on the AAHSA website allows users to search for nursing facilities by state. Many state nursing facility associations have similar tools.

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Information on characteristics of a specific nursing facility, characteristics of the residents, and information reflecting quality of care can be obtained on the HCFA website (*http://www.medicare.gov/NHCompare/Home.asp*). This website allows the user to search for nursing facilities by state, county, city, or specific facility. The information provided is quite detailed and is available for all Medicare and Medicaid certified facilities in the United States.

For information on assisted living facilities, one of the best sites is Assisted Living INFO (*http://www.assistedlivinginfo.com)*. The user is able to search for assisted living facilities by state, city/county, name of facility, facility management, or by special needs. The site also provides a mapping feature that shows the precise location of the facility.

The Care Manager and Resource Development

In rural areas, the care manager may have few services available and funding options tend to be more limited than in urban areas. It is imperative that rural care managers understand basic rural development principles and effective ways to initiate new services. Some useful sites on rural health and rural development, including service development are:

Rural Information Center Health Services *(RICHS)* (*http://www.nal.usda.gov/ric/richs)*. This website is a joint project of the Office of Rural Health Policy and the National Agriculture Library. It is an excellent source on rural health issues, including retention of health care personnel, programs for special populations, facilities administration, network development and innovative service delivery.

The U.S. Department of Agriculture *(USDA)* (*http://www.usda.gov)* site highlights many aspects of rural development. Of particular interest to care managers are sections on Rural Development; Food, Nutrition and Consumer Services; and Research, Education, and Economics. The latter section has information on the Cooperative Extension Services in each state. The Cooperative Extension Service can be a valuable partner for rural care managers, assisting them with consumer education, resource identification and resource development. The USDA site also has articles from the journal ***Rural America*** available online, and the articles can be downloaded and printed.

The W. K. Kellogg Collection of Rural Community Development Resources website (*http://www.unl.edu/kellogg)* is sponsored by The Heartland Center for Leadership Development. Abstracts of materials relating to rural development and rural health are provided along with information on how to obtain the materials.

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The Care Manager: A Student and An Educator

Informational and Educational Resources for the Care Manager

The clients of care managers usually have multiple health problems, as well as social and economic challenges. A major part of geriatric care management is the management of health problems in order to reduce the disabling effects of health conditions and to reduce the need for services. It is imperative that the care manager be able to identify health risks and adverse health conditions early and institute proper referrals.

There are a number of resources on health and social concerns. The medical libraries of larger hospitals and medical schools have books and journals, as well as librarians who are quite knowledgeable in obtaining health-related information. For those with access to the Internet, the best source for information on the latest books and journal articles is the National Library of Medicine (NLM) (*http://www.nlm.nih.gov*). This site is open to anyone and provides information on all holdings of the NLM, and links to MEDLINE, the NLM database containing bibliographic citations and abstracts from more than 4000 biomedical journals. The NLM website also provides information on how to obtain books and copies of journal articles through interlibrary loan or directly from online resources. *MEDLINEplus* is also available through the NLM site. This is a searchable database that provides information on a vast number of health conditions and medications, as well as links to other websites where one can search for physicians by name, specialty and geographic area. There are also links to websites that provide information on healthcare and long-

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term care facilities and on quality indicators for specific facilities.

For information relating to the latest research on health conditions, mental health, aging and other health-relevant issues, the website for the National Institutes of Health (*http://www.nih.gov*) is the place to turn. From the main site, there are links to all of the institutes and to other health organizations. There is also a section that provides consumer health publications on a vast array of topics. These are easily printable and can be used by care managers for consumer education.

An excellent site for consumers and professionals is *Healthfinder http://www.healthfinder.gov*, a website provided by the U.S. Department of Health and Human Services. It is a vast resource of information on specific health conditions, individual health providers and health organizations, current health literature and much more.

For common health conditions, one can usually find an organization that focuses on the particular condition and provides up-to-date information on the latest in research, treatment and support relating to the condition. Examples of such organizations include the Alzheimer's Disease and Related Disorders Association (*http://www.alz.org);* American Heart Association (*http://www.americanheart.org)* and National Diabetes Association (*http://www. diabetes.org).* The Administration on Aging's website *http://www.aoa.gov/aoa/DIR/browse.html)* has links to other such organizations.

AgeLine (*http://research.aarp.org/ageline)* is a searchable bibliographic database. This database, produced by AARP, houses abstracts on articles related to social, psychological, health, and economic issues of aging. It provides abstracts and full-text copies of reports produced by AARP. It also provides information for consumers and is an excellent reference source that care managers can provide to clients and their families. Reports on everything from the preparedness of consumers for e-commerce to assisted living facility regulation recommendations are available on this site.

The website for the *National Association of Professional Geriatric Care Managers* (*http://www.caremanager.org/gcm/ProfCareManagers.htm)* is a valuable resource about care management and houses a directory of care managers throughout the country. This can be an excellent source for developing a consultation network among rural care managers, and for referral. It is possible to search for care managers by name, organization, city, state, zip code, or areas of experience.

Consumer Education and Support

Care managers have the responsibility of ensuring that the client and/or caregivers are knowledgeable about the problems and issues they are confronting. Education empowers them to be active participants in the care management process. There are several websites that provide information and support services to elders.

ElderWeb (http://www.elderweb.com) is a comprehensive site with information on everything from finance and law to health to living arrangements. It provides regional and state information on a broad spectrum of aging issues. A text only version of the site is available for those with older browsers or computers.

There are a number of sites specifically for caregivers. These websites offer caregivers information to assist them in their role, and opportunities to network with each other for support and consultation. These sites include the *National Family Caregivers Association (http://www.nfcacares.org),* the *National Alliance for Caregiving (http://www.caregiving.org), Caregiver.Com* (*http://www.caregiver.com*), *Hospice Net* (*http://www. hospicenet.org*), *Family Caregiver Alliance* (*http://www.caregiver.org*) and *ALZwell* (*http://www.alzwell.com*).

Before recommending a particular site, the care manager should review the site to determine if it is monitored for accuracy by knowledgeable persons, if it is a legitimate consumer site and not intended as a tool to sell a particular product or treatment and if it will provide information and support needed by the client/caregiver. Persons using online sites should always be warned to be wary of the information and to check out products and treatment recommendations with their health providers.

Summary

Rural care managers must be committed to self-directed learning and willing to look both inside and outside the local community for services and assistance, to seek and embrace new modalities of information dissemination and education, and to experiment with nontraditional service models to meet their clients' needs. Information is available to help rural care managers. The challenge is to get that information, given the isolation and limited access to resources so often encountered in rural areas. As an addition to the traditional means of providing information, namely books, journals, and publications, the Internet offers access to information that can be independent of geographic location. The purpose of this compilation is to provide rural care managers with a guide to some of the resources available, and to give rural care managers a starting-point in their search for knowledge and services.

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