Home and Community Based Alternatives to Nursing Home Care in Rural Communities

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Abstract

Most dependent elders and familial caregivers’ desire that their elderly loved one remain in their own homes and communities to delay institutionalization. Without appropriate supports the ability to safely maintain elderly members in the community decreases. Rural elders face additional risks as they may be isolated physically and socially from both informal and formal support systems. An examination of Pennsylvania’s rural home and community based (HCB) alternatives to nursing home care identified large numbers of individuals unserved by the existing care system. Crucial policy recommendations include the introduction, and appropriate funding of innovative care models that exist in other rural states to expand the availability of HCB alternatives and target intra-agency barrier.

Keywords: Rural Services, Policy, Alternatives to Nursing Home Care, Home and Community-based Services,

Problem Statement

America is aging and the anticipated end of life care needs for seniors are growing. According to the 2010 Census, the U.S. experienced a 15.1 percent increase in the age 65 and over population (Werner, 2011). Pennsylvania has the fourth highest population of those age 65 and over in the nation (U.S. Census, 2010). From 2000 to 2010, the greatest area of growth occurred in the 85 and older population in Pennsylvania (U.S. Census, 2010). This is a significant trend and is worth examining as more family and societal support may be required as the population ages. The need to understand this phenomenon is even more pressing in rural communities where geographic distance and a more limited base of service providers significantly impact successful aging in place (Melnick, Shanks-McElroy & Chechotka-McQuade, 2004).

In rural Pennsylvania, the elderly are older than the elderly in urban areas. Per data from the 2010 Census, 17 percent of the rural population was 65 years old and older compared to 15 percent of the urban population. From 2000 to 2010, the number of rural seniors increased by 5 percent, while the number of urban seniors increased by 1 percent.

Rural seniors also are more likely to be poorer and have more health care needs than urban seniors (Hutchison, Hawes and Williams, 2010; Colburn & Bolda, 2001). Additionally, the rural elderly continue to face a more challenging environment in terms of access to less expensive home and community-based (HCB) care.

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The Pennsylvania Department of Aging (2011) defines home and community-based care services as services covering a wide range of needs available in communities. These services include: home health care; personal care, such as providing assistance with bathing, dressing, eating, grooming, and toileting; health care support services, such as housekeeping, shopping assistance, laundry and mending; respite care (caregiver relief); transportation and other routine household chores as necessary to maintain a consumer’s health, safety and ability to remain in the home; and home-delivered meals prepared at a central location and delivered to a person’s home (PA Department of Aging, 2011). While there is a larger supply (per elder) of nursing home beds in rural areas than urban areas, fewer HCB services and residential care options are available (Colbourn and Bolda, 2001). Rural seniors are also less likely to have private pay insurance to help offset the cost of HCB care (Hutchison et al., 2010).

Rural elders have more chronic health conditions, such as arthritis, hypertension, diabetes and heart disease (Hutchison, et al, 2010), and a higher proportion of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) impairments than their urban counterparts (Hutchison et al., 2010). Requiring assistance from either family caregivers or institutionalized support, whether through HCB services, such as meals on wheels, and/or nursing and personal care or residential care services, such as assisted living or personal care home support, becomes paramount to staying within their homes and in their communities.

The myth that there are large families in rural areas with many available caregivers for both the young and the old, as popularized in the media, is no truer in rural areas than in urban areas (Hutchison et al., 2010). Although there is a national trend toward the reemergence of the multigenerational household, it is largely driven by adult children remaining or moving back in with their parents due to the recent downturn in the U.S. economy. Only about 20 percent of the 65 and older generation live within multigenerational households, a slight increase from 17 percent in the 1990s (Pew Research and Social and Demographic Trends, 2010).

In addition, the barriers of geographic distance to available services combined with accessibility issues and poor health status leave little recourse for rural seniors who want to stay in their own homes. The likelihood of nursing home admission may increase for rural seniors who do not have family and/or social support. Until the advent of the Medicaid Waiver program, the lack of Medicare coverage for home and community-based services further limited access to services for the rural elderly who lacked disposable income to purchase services. While the Medicaid Waiver program allows for a variety of HCB services, the availability of services varies from state to state (Hutchison et al., 2010). Rural seniors have a much narrower range of services and confront greater barriers to accessing care than their urban counterparts (Hutchison et al., 2010).

Even with the provision of HCB services through the Medicaid Waiver program, the Medicaid system still supports the predominant structure of the costlier institutionalization of frail seniors. Keeping older rural adults in the community is more cost effective than institutionalization (Pennsylvania Homecare Association, 2011; Krout, 1994). However, according to the Pennsylvania Homecare Association (2011), “although the elderly and adults with disabilities represent just 35 percent of the Medicaid total budget, the cost of their care is disproportionate, representing 69 percent of Medicaid’s total budget. These high costs are mostly attributed to nursing home care - the most expensive type of care and least desired” (p.7).

The development of rural HCB services has been limited because of the lack of personal income and/or private insurance to purchase services and the absence of sufficient county and state funds to finance service provision. Nearly 16 percent of those aged 65 and older live below the poverty level (Short, 2010). For seniors who are 85 years and older, the probability of living in poverty continues to increase each year. Boulton (2012) noted that a study by the Employee Benefit Research Institute estimated 14.6 percent of people 85 and older, or roughly one in seven, are living in poverty, and the percentage increased each year between 2001 and 2009.

Barriers to service development and delivery also exist in rural culture itself. Many of the attitudes that have contributed to survival in rural areas, such as self-reliance, individualism, family orientation and the belief that family should be responsible for care, may also decrease the willingness of the rural elderly to seek and receive assistance and of the rural community to provide services (Hutchison et al., 2010; Connell et al., 1996). Citizens of rural communities may regard HCB services as hand-outs or welfare, misconceptions that create an unfavorable situation for developing and maintaining services (Melnick et al., 2004). Education may play a key role in alleviating these attitudinal barriers.
If HCB care services are to be a valuable service to Pennsylvania’s rural seniors, it is important to understand how this population is currently being served, and may effectively be served in the future, from the experience of coordinating agencies, such as local Area Agencies on Aging, the Department of Public Welfare and providers currently in existence. For this reason, the study had five goals:

- Determine the scope and magnitude of HCB care alternatives to nursing homes currently available in rural Pennsylvania.
- Determine the current need for rural HCB care alternatives to nursing homes among two constituent groups: individuals aged 60 years and over, who require assistance with one or more ADL skills, and who cannot, safely, remain independent within a community setting; and persons with disabilities who are under age 60 and who meet the aforementioned criteria.
- Compare the present supply of, and demand for, rural HCB care alternatives to nursing homes and identify existing and potential gaps in service, and project supply and demand statistics for the upcoming 2-5-year period...
- Identify funding issues that enhance or impede the provision of rural HCB care alternatives to nursing homes in Pennsylvania.
- Formulate policy considerations regarding the development, growth and maintenance of rural HCB care alternatives to nursing homes in Pennsylvania.

Methodology

This research used a theoretical model consistent with the Wan and Ferraro (1991) model for assessing the impact of HCB health care policies and programs for older adults. This model is used consistently within the literature (Estes & Swan, 1992; Kelley-Gillespie, 2009; Rowan et al., 2011; Rudd, 1996; Van Beveren & Hetherington, 1995) and measures four major components of HCB service delivery: equity, accessibility, quality, and efficiency. Equity refers to the extent that adequate and responsive health services are available for those in need of care, irrespective of the ability to pay. Accessibility refers to the degree to which a person has adequate access to either preventive or curative care. The characteristic of quality includes three sub-components of service delivery: continuity, acceptability, and effectiveness. Continuity refers to consistency in providing needed care without interruption. Acceptability refers to the degree to which an individual has been given choices in selecting the type of care desired, as well as the perceived desirability of participation in a program or medical intervention. Effectiveness is a broad term used to measure the degree to which health service programs have succeeded in meeting client or organizational goals, as well as whether the same outcome can be achieved at a lower cost. The features assessed in the study are summarized in Figure 1.

**Figure 1: Wan and Ferraro (1991) Theoretical Model**

![Wan and Ferraro (1991) Theoretical Model](image)

Client characteristics including total unduplicated clients; age; gender; living arrangements (alone, with family, etc.); average length of time awaiting participation in services; and average length of program participation in months were evaluated for aggregate reporting.
Sampling.

Fifty-seven (57) counties were included in the study sample, including 48 identified as rural by The Center for Rural Pennsylvania (counties with fewer than 284 people per square mile) and 9 urban counties adjacent to the rural counties in the sample. Those urban counties were included because they housed HCB services provider agencies that serve clients who reside in Pennsylvania’s rural counties.

To identify all current providers of HCB care alternatives to nursing homes, the researchers initially contacted 746 stakeholders in the 57 counties involved in the study. Those stakeholders included: County Area Agencies on Aging (AAA), Mental Health/Mental Retardation Base Service Units (MH/MR), state and county elected officials, faith-based service providers, Senior Center directors, and senior advocacy organizations. In total, 349 HCB provider agencies were identified and invited to participate in the study. One hundred and twenty completed surveys were returned, representing a 34.4% participation rate.

To develop concrete and consistent client characteristic statistics with which to compare the study data, the researchers used 2010 Census data for each county, and documented the total numbers of individuals who met the study criteria. They then used the findings from the Pennsylvania Department of Aging’s report, Pennsylvania State Plan on Aging, 2008-2012, which indicated that 39.3 percent of eligible individuals may be considered as viable candidates for HCB care services. The researchers used this rate to calculate county projections of rural constituents who would be viable candidates for HCB care alternatives to nursing homes.

Results

Total unduplicated consumers in 2011.

Findings from this study indicated that the total number of unduplicated clients served in the rural counties of Pennsylvania by AAs, MH/MR units and individual service providers was 126,461. The total unduplicated clients over age 60 was 88,663 and the total under age 60 was 31,062 (6,736 of the total unduplicated clients are not included in the under 60 or over 60 age group breakdowns because not all reporting agencies collected client age data).

Range and types of services offered by HCB care providers.

HCB provider respondents offered a variety of services for consumers. On average, participating HCB care providers reported offering 3.8 types of services for consumers, with a range of one to eight services. Seventy-seven percent of HCB providers were nonprofit agencies and individual HCB care provider budgets varied significantly with the following data noted:

Equity, accessibility, quality and efficiency of services provided.
Equity

Nearly 19% of participant HCB providers cover multiple counties with lengthy distances in between. Fifteen counties (26.8 percent) had no identifiable HCB that provided services, and an additional 12.5 percent had only one identifiable HCB. These findings raise some important concerns regarding the adequacy of available services for individuals and families who reside in counties with few or no HCB providers.

Eligibility criteria as a measure of equity were assessed for individual programs provided by HCB participants. In addition to meeting the age criteria for participation (over age 60 for aging services and over age 18 for MH/MR related services), several additional eligibility criteria were noted in the qualitative data collected. Most notable was payment source: if the individual was not eligible for an established service, such as home health (paid by Medicare or private insurance), or did not meet the requirements for a service provided by the AAAs, the person would have to pay privately. The research results strongly indicate that most of the consumers served received services paid by some form of government funding. To be eligible for government-paid services, recipients must require medically necessary services. This form of service eligibility is commonly referred to as the “medical model,” a community health care service providing non-acute care patterned after the diagnosis/treatment model of physicians (Melnick et al., 2004). Therefore, eligibility for service access often hinges on a documented need for intensive, skilled nursing services. Consumers who require only non-medically based services designed to support independence and the completion of ADL are ineligible to receive HCB services, such as adult day services, personal care, and home support, unless they possess private funds to pay for services. This finding suggests that all Pennsylvania seniors and those under 60 with a disability must be significantly impaired to receive supported/funded services. These criteria have the potential to put consumers at risk. The consumers’ health may deteriorate as they await services that may never materialize and thus they may require institutionalization. However, those consumers who can afford to pay privately have a better chance of remaining in their home for longer periods.

Accessibility

The findings noted above regarding lengthy distances between providers and clients and the lack of HCB provider agencies in all counties also raise some important concerns regarding the accessibility of available services for individuals and families who reside in rural counties. With an increased need to include travel time as a component of care scheduling, and as an important factor in staff recruitment, retention, and compensation, individuals and families who reside in counties without an adequate supply of HCB care providers may be unable to access services when staff cannot be dispatched efficiently and cost effectively from a distant geographic locale.

Waiting list occupancy for services was also used as a measure of program accessibility. The research found that, in 2011, 83 unduplicated individuals under age 60 and 1,439 unduplicated individuals over age 60 occupied a service waiting list, for a total of 1,522 individuals. Study participants were also asked to identify the total number of individuals on waiting lists for individual programs, along with average duration of waiting list occupancy and range of months spent waiting for services. Not surprisingly, those services with the largest waiting lists included personal care services, home support services, and medication management. Because the individuals on waiting lists for those services do not require skilled nursing services, which would provide a gateway to non-medically necessary services, agencies do not have adequate resources to make those services available in the numbers they are needed or with the funding sources available to individuals and families in the community. The length of time consumers wait for services could not be evaluated since many services are not consistently recorded by agencies. This information would have helped to understand the true scope of individuals waiting for services but its absence does not detract from the study findings.

Lastly, agencies reported problems with recruitment and retention of staff due to several consistent issues: undesirability of work duties, need for evening and overnight work hours, long travel requirements to reach clients’ homes, low reimbursement rates for staff, and limited availability of full-time work due to a lack of funding for non-medically based services. Qualitatively, personal care service providers reported barriers to recruiting and retaining staff because of less than desirable work duties, travel requirements in rural areas, and evening and overnight work hours.
Agencies that provide congregate meals indicated that staff recruitment and retention were negatively impacted by uncompetitive wages, and personal assistance service providers had trouble retaining staff because of limited work hours. This concern is compounded by the same lack of desirable work duties and travel requirements cited by personal care service providers. This finding is consistent with research conducted by Melnick et al. (2004).

Quality

Quality includes three sub-components of service delivery: continuity, acceptability, and effectiveness. Continuity of care is important to all service recipients, but is especially important to older people, who tend to prefer familiar environments and stable social relationships (Wan and Ferraro, 1991). Duration of program participation was used to assess continuity and participants were asked to identify the average duration of participation for each program, along with the range of participation duration for all clients.

For programs reporting participation duration, it appeared that once an individual began to receive services, he/she remained on the agency caseload for a minimum of 13.5 months. This indicates a positive level of continuity of care. Respondents were also asked to provide the average number of unduplicated staff who provided care for a specific client within a given week. However, respondents were unable to provide the information because records were not available.

Respondents were asked to identify barriers to client service use related to problems with perceived desirability issues. HCB care providers indicated a disconnect between consumer and family perceptions of service need that negatively impacts service use. Personal care service providers and adult day service providers noted that while family members may want a client to have services, the client does not recognize the need for services and is not willing to participate.

In addition, HCB care providers reported that both family and consumers were deterred from using services due to perceptions of undesirability related to the presence of severely impaired peers in programs like adult day services. Lastly, as a more generalized observation, respondents reported that in-home services were regarded as an invasion of privacy for some consumers.

Efficiency

Since this study could not compare outcomes between HCB services to nursing home and other institutionalized care, the research could not address the issue of efficiency. Additionally, it would have been difficult to compare service providers across counties within the confines of this study since issues, such as geographic location and competition between providers, impact service provision costs. A consideration would be to further explore the question of efficiency in future research.

Comparison of supply of and demand for rural HCB care alternatives to nursing homes and identification of existing and potential gaps in service.

To analyze the supply of and demand for rural HCB care alternatives, the researchers estimated for each county the current number of rural constituents who could be eligible for HCB care alternatives to nursing homes if such services existed. The researchers used data from the 2008-2011 American Community Survey (U.S. Census, 2012). The researchers did not include the nine adjacent urban counties in this part of the analysis, and, due to the HCB care focus of this study, only included non-institutionalized persons with disabilities, age 18-64 years, and non-institutionalized individuals over the age of 65 who are potential HCB care consumers in the analysis.

To project the number of “viable candidates” for HCB care programs, the researchers used the Pennsylvania Department of Aging’s (Pennsylvania State Plan on Aging, 2008-2012) rate of 39.3 percent of eligible individuals that are likely to use HCB care services at any particular time.

For the study, respondent agencies and organizations identified a total of 126,461 unduplicated individuals who received HCB care services in 2011. When compared with ACS and Census-based projections of 319,450 viable candidates for HCB care services in Pennsylvania rural counties, the researchers found that 192,989 viable candidates for HCB care services are unsaved by the existing service system.
Conclusions

Strengths and Weaknesses of the Current Rural HCB Care Network.

The presence of 349 HCB care alternative providers, with an estimated service ratio of 9.7 HCB care agencies per county, to provide services in Pennsylvania’s 48 rural counties may initially be regarded as a strength. However, 26.8% of those counties had no identifiable HCB care provider that offered services, and an additional 12.5% had only one identifiable HCB care provider. While not necessarily indicative of inadequate service, these findings raise some important concerns regarding the sufficiency of available services for individuals and families who reside in these counties. The distances that home health workers must travel to reach consumers negatively impacts efficiency as more time is spent on the road. To combat this weakness, providers must either hire more workers, which increases costs, or serve fewer individuals. Given the problems with recruiting and retaining staff, serving fewer individuals is the most likely outcome.

A second strength involves the range of services offered by HCB care providers in rural Pennsylvania counties. In general, HCB care agencies provided anywhere from one to eight services. However, given the eligibility criteria for services, which are based on a documented need for intensive skilled nursing services, consumers who require only non-medically based services designed to support independence and the completion of ADL are ineligible to receive HCB care services. This finding suggests that rural seniors and those under 60 with a disability must be significantly impaired to access the broad spectrum of services. This puts these consumers at significant physical risk as they wait for services that may never materialize and thus may require institutionalization.

Compounding difficulties in accessing non-medically based services is the funding model for services that exist in Pennsylvania. Nearly 16 percent of rural seniors live below the poverty level (Short, 2011). In Pennsylvania rural counties, 54% of HCB care services provided to individuals over age 60 and individuals under age 60 with a disability were funded by payments through the Departments of Aging and Public Welfare.

While duration of participation in HCB care programs is lengthy once initiated (a minimum of 13.5 months in the study sample), for many consumers, services are only available on a private-pay basis. Although this study did not specifically collect data regarding costs of services, service funding suggests an overreliance on private pay for all non-medically based services. This excludes a large proportion of rural consumers who would be considered viable HCB care program participants who lack disposable income to purchase services.

Geographic distance for seniors and individuals with disabilities to travel to community-based services is another weakness in the rural care network. Many seniors and individuals with disabilities may willingly opt out of services if the travel time is too long or if transportation is not available (Melnick et al., 2004).

In reviewing the conclusions of this research, study limitations must be kept in mind. While data collection with individual HCB care providers was completed to provide corroboration of the data provided by AAAs, MH/MR units, and DPW, the sample size of these participants was a concern. However, the strong level of agreement among all the data helped assure the reliability of the data. Input from larger numbers of HCB care providers would have provided important new insights into the models of service delivery and payment that currently exist.

Policy Considerations

The researchers offer the following recommendations to address the barriers to the delivery of rural home and community-based care alternatives to nursing homes. First, review and expand Life Centers, nationally known as the Program of All-Inclusive Care, or PACE. In a response to the demands to establish cost-effective care for the elderly in this country, the federal government created the Rural Program of All-Inclusive Care for the Elderly (PACE) Pilot Grant Program. The program was established by Congress under the Deficit Reduction Act of 2005 and administered by the Centers for Medicare and Medicaid Services (CMS) and provided 15 providers with start-up funds to develop PACE organizations serving rural elders. This program is an integrated, acute and long-term care model for frail, disabled adults living in the community. To avoid confusion with the medication reimbursement PACE program in Pennsylvania, the program is known as LIFE Centers in Pennsylvania. One of the initially funded sites was Geisinger Health System Foundation in Danville, Pa., which currently operates Life Geisinger in Scranton, Pa.
Pennsylvania has 17 Life (PACE) program providers that operate 30 centers in 18 counties (Personal Communication, Office of Long Term Living, Pennsylvania Department of Public Welfare, January 29, 2013). The PACE program has demonstrated that “their enrollees have lower rates of nursing home admissions, shorter hospital stays, lower mortality rates, and better self-reported health compared to non-PACE populations” (Petigara & Anderson, 2009). As this program is a collaborative effort between the federal government and the Pennsylvania Departments of Public Welfare and Aging, it demonstrates collaboration and cooperation in a financially viable and expedient delivery model. Expansion of these services to reach all viable, potential consumers would allow for consolidation and coordination of services for all elders, including those who reside in rural communities.

Second, establish the Minnesota “Health Care Home” model of care provision in rural counties of Pennsylvania. A study conducted by the Minnesota Department of Health (2009) noted that health care in the U.S. is highly fragmented and overly reliant on specialized care, that care is often excessive and inefficient, and that the payment system creates incentives for procedures rather than wellness and prevention. Minnesota set out in 2008 to redesign health care in general and in particular, to rural areas. Minnesota’s response came in the form of the “Health Care Home” (Minnesota Department of Health, 2009). The Health Care Home first emerged as a model of care for children in 1967. It has since been adapted to encompass an elderly, rural population in the Minnesota model.

The major principles of this model are, “physician directed medical practice; personal doctor for every patient; comprehensive; coordinated and family-centered; accessible, continuous and high quality; compassionate and culturally effective; and a payment system recognizing the added value for patients” (Minnesota Department of Health, 2009). This model puts the patient or service recipient at the center of the care process where they remain the primary focus. This model appears to not only be a cost effective way to finance services for the elderly and people with disabilities but also puts the locus of control and the focus of the care squarely on the care recipient.

Third, increase efforts to locate providers in all counties. The researchers are aware of the significant barriers to achieving this goal but it would appear that not having access to a local provider negatively impacts cost and provision of services. In terms of home care services, providers that are located closer to clients might allow for a reduction in amount of time individuals spend on the waiting list for services. Likewise, it would be beneficial to provide community-based services, such as Adult Day Care, that are located nearer to potential consumers who are old, frail, and unable to physically withstand a long commute to and from services.

Fourth, increase funding for preventative services that delay institutionalization. Per the data, it appears that consumers must be severely medically impaired to receive home and/or community-based services. Medicine in general has been moving toward a “preventative” model of care and the need to apply that same philosophy to the elderly and people with disabilities is evident. Preventing and prolonging deterioration seems to be not only more humane but more cost effective. Efforts should be made to study the hypothesis that when funds are redirected toward prevention, premature institutionalization can be avoided.

Fifth, address barriers to recruiting and retaining staff. Agencies reported several recruitment and retention issues that, if left unresolved, will negatively impact provision of rural home and community-based services. These barriers are often exacerbated by the fluidity and lack of secure state funding from year to year leaves much confusion and uncertainty within the system. While state budgets are developed yearly and are subject to ongoing changes, yearly reductions are detrimental to the provision of services overall and particularly in rural areas.

And last, consider standardizing records and record keeping. Many providers, both at the public agency level and direct service level, reported difficulties in identifying information requested for this study such as unduplicated persons served and accurate data regarding the provision of services. This makes any analysis of budget and cost effectiveness difficult and does not allow costs to be analyzed. Therefore, it is impossible to say whether services provided to rural elders are cost effective.
References


