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# Rural Older Appalachian Women's Formal Patterns of Care

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## Abstract

The purpose of this qualitative descriptive study was to explore rural older Appalachian women's decision-making regarding use of, and experiences with, formal health care services. Nineteen rural Appalachian women living alone were interviewed using a semi-structured interview format. Interviews were then reviewed to identify patterns and themes. Decision making themes included: "anticipating possibilities," "doing what is needed," "listening to and valuing the views of others," and "seeing no other choice." Utilization themes were: "using on my own terms," "dealing with barriers," and "meeting a need." Study findings support the importance for providers, educators, and researchers to recognize cultural influences on health and service utilization decisions.


***Keywords: Appalachia, older women, health care, service utilization***

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## Introduction

Women age 75 and above have been identified as a socially vulnerable population.[1] Factors that contribute to this vulnerability are living alone, poverty, poor health, and rural residence. In 2000, there were over 421,000 women aged 65 and older living in Tennessee, with approximately 12,000 over the age of 75 living in the Northeast region.[2] National Statistics show that more than 49% of older women age 75 and older live alone.[3] Unmarried elders over age 65 living alone have an overall poverty rate greater than 19%.[4] However, women living alone in rural areas are most likely to be living in or near poverty levels with nearly double the rate of poverty when compared to elder, urban men.[5] Poverty rates are even greater in Appalachia. Further, elders living in rural areas such as Tennessee's Northeast region have few formal care resources at their disposal. However, even when resources are available, many elders tend to underutilize them.[6-8] Little research exists that describes factors influencing decision-making regarding use of, or experiences with, formal care services by

older Appalachian women who live alone, despite the fact that this group meets all criteria for social vulnerability and do not utilize many available community and health services.[9] Therefore, the purpose of this qualitative descriptive study was to explore older rural Appalachian women's decision-making process and experiences with formal care regarding use of formal health care and assistive services. Understanding of this process and experience from the participants' view may add information regarding service underutilization by this group of elders.

## Literature Review

With poorer economic and health status, elderly women may require assistance with maintaining health, well-being, and independence. Older women and elders in general tend to underutilize available community resources even when these services are available.[6-8] Reasons for this underutilization are varied and sometimes obscure. Studies have explored the effects of culture and ethnicity on service utilization in Soviet Union Immigrant,[10] Asian/Pacific Islander,[11] African-American,[12] and Mexican-American[13] elders. A combination of select life circumstances and cultural norms and beliefs accounted for service utilization patterns in these groups. Both Black and White diabetic elders were found to have low service use, especially of nutritional and recreational services in another study,[6] but no reasons were cited for this low use. Culture, specifically attitudes and beliefs and client's evaluation of aspects of service delivery, were predictors of respite service use in a study comparing African-American, Hispanic/Latino, and White elders.[7] Age, race, health conditions, income adequacy, payment source, transportation capability, health conditions, and function were predictors of nutritional service use among African-American and low income rural elders in another study.[14] One study explored attitudes of adults about community-based services and found that the quality of programs or staff, security, cost and eligibility requirements, transportation and logistical elements all affected use of such services.[15] Previous research[16]

showed that demographic characteristics were less indicative of service use among elderly women than were social influences such as being widowed or living alone. No studies have been found that have specifically addressed the decision making process of elders to use services or their experiences with these services.

The term Appalachian has been used to describe the people "born and raised" in or near the Appalachian Mountains. Much was written about Appalachia during the 1960s through the 1980s but some authors feel that no consensus has been reached as to what specific behaviors belong to the culture or even if such a culture exists.[17] However, even though there is wide diversity within the groups that populate this region, there are some similarities in beliefs and practices. These dominant similarities in values, beliefs, and traditions as well as the differences among the group must be considered when providing health care.[18]

The perception of Appalachia is that of a "cabin in the woods, with a tireless car sitting in the yard."[19 p.32] However, the reality is that studies of Appalachians have identified them as possessing enduring distinct cultural values including individualism, pride, loyalty, caring, family-orientation, religiousness, hardiness, independence, honesty, patriotism, resourcefulness, and self-reliance.[20-23] In the Appalachian culture, family members frequently live in close proximity and relatives are frequently sought for advice on most aspects of life.[24-25] Elders are respected and honored in the Appalachian family and usually elders live close to or with their children when they are no longer able to care for themselves.

Appalachia has one of the highest aging populations. Approximately 48% of Tennesseeans live in rural areas with 14% of these rural residents over age 65.[26-27] This has given rise to challenges for health-care delivery to this cultural group.[6] Appalachian rural areas continue to have high unemployment rates above the national average, with some Appalachian rural areas having rates as high as 37 to 50 percent as well as a large population living in poverty.[28] In Tennessee, the rural counties of Johnson and Hancock have poverty

rates of 22.8% and 30%, compared to 10% for urban areas of the state.[29]

Studies have been reported on Appalachians in several areas, including: mental health, urban child welfare, and developmental disabilities[30-36]; Appalachian rich cultural heritage of strong family bonds and traditions[37-38]; and children, adolescents, and childbearing families.[39-43] Other studies have concentrated on spirituality of older Appalachian adults.[44-45] Additional studies have focused on describing Appalachian culture, health problems experienced by Appalachians, barriers to health care, and communication recommendations for healthcare providers.[38-50] Little research was found in either nursing or the social sciences that addressed service use by elderly populations in Appalachia or on rural older Appalachian women who live alone. One phenomenological inquiry of the relational experiences of elderly women living alone in rural communities was found.[51] However, the women in this study were located in New York State.

*Theoretical Framework.* Madeline Leininger's Theory of Culture Care Diversity and Universality[52] provided a perspective for interpreting the experiences of the older women and a background for sensitivity to the findings. This theory emphasizes caring and care as central concepts, with consideration of the multiplicity of societal and cultural factors that influence choices by people regarding care modalities. Since this study explores choices regarding services made by a specific cultural group of women, the framework was deemed appropriate. Within the framework of this theory, there are two types of caring in any culture: generic and professional. The generic type of care is a folk, indigenous, or naturalistic type, and refers to traditional health care or cure practices, such as self-care practices that the women might use. The professional type of care system refers to professional care or cure services offered by diverse health care personnel.[52] In this study, the professional care was the formal care services the women used. For this study, formal care services were defined as those offered by agencies or service organizations. The selected theoretical viewpoint allowed insight into the

impact of Appalachian culture on older women's experiences, including interactions, thoughts, and feelings associated with seeking help from formal sources, providing a new perspective and understanding of this process.

## Methods

Older women, living alone in two predominantly rural northeast Tennessee counties were recruited for this study. Eligibility requirements included: a) women 75 years of age and older who live alone. b) have always lived in the northeast Tennessee Appalachian region, and c) reside in Johnson or Hancock counties. Snowball sampling methodology and referrals from nurse-managed clinics were used to obtain the sample participants. While not a selection criterion, all of the participants in this study were Caucasian.

Two research questions guided this study: a) To what extent do traditional Appalachian values influence decisions by older rural Appalachian women living alone to use formal services? and b) What are the experiences of these rural Appalachian women with formal services? Using a qualitative, descriptive study design, study participants were interviewed in their homes using a semi-structured interview format to elicit information regarding decision making regarding use and experiences with formal care systems within the context of the participant's culture. The qualitative descriptive design was selected for this study because of its strength in revealing a depth of meaning and a respect for individual knowing.[53] Participant rights and confidentiality were protected and approval of the University Institutional Review Board (IRB) was obtained prior to commencement of the study. The nurse co-investigators contacted potential participants by telephone and the study was explained. If the women consented, interviews were scheduled at a mutually agreeable place and time. At the time of face-to-face interviews, the study was again explained and participants signed a consent form. The semi-structured 60-90 minute interviews were tape recorded and transcribed verbatim. Prior to the semi-structured interview, demographic questions regarding age, educational level, economic status

(sources of income), number of children, insurance, and time lived alone were asked. The semi-structured questions included: a) Tell me about a time that you sought help outside of your family, friends, or neighbors; b) What was the experience like? c) Would you ask for help from the same source again? Why or why not? d) Tell me about how you feel about asking others for help; and e) Tell me about any persons or resources in your community that help you to live at home.

Transcribed interviews were reviewed by the co-investigators line-by-line and each individual event or description was given a name that represented the phenomenon. Incidents were compared with like incidents as analysis progressed in order to group and label similar phenomena. Data were then collapsed and similar concepts were grouped into categories and given names derived from the data. Major patterns or themes were identified and other categories were grouped as subcategories under the respective two major themes. Constant comparative analysis was utilized whereby coding was constantly compared to transcripts to assure accuracy. Patterns and themes that emerged were described and confirmed by the co-investigators. The latent quality of the data was explored, but the data was not re-presented in terms other than the participant's own words.[54] The outcome of the analysis was a comprehensive and accurate summary that detailed the participants' stories. Rigor was established through: cross-checking of participant's stories with emerging codes; returning to the participants for clarification, if necessary; critical self-reflection of the researchers' perceptions; and review of memos and logs.

## Results

Nineteen Caucasian Appalachian women over the age of 75 participated in this study. Demographic characteristics are summarized in Table 1. The women reported a variety of economic sources: Social Security, Veterans Administration, retirement, savings, and income from properties. Four of the women were subsisting entirely on Social Security payments. All women were covered by Medicare, and nine had supplemental insurance of some type. Six women (32%) reported difficulty

"making ends meet."

**Table 1**
**Demographic Characteristics of Older Appalachian Women**

| Demographic | Mean | Range |
|---|---|---|
| Age | 80.2 years | 75-90 years |
| Educational level | 10.5 years | Grade 4-Master's |
| Length of time alone | 11.04 years | 1-26 years |
| No. Children | 1.9 | 0-5 |

Although not asked specifically, generally this group of women self-reported themselves as being healthy. They were continuing to live in their own homes, prepare their own meals, do the majority of their own light housekeeping, visit friends, and do the things that they considered important. Many of the women kept small gardens or flower beds and all except one were quite active physically.

Two major categories of themes emerged from the data analysis: decision-making themes or formal care utilization themes. Decision-making themes answered the first research question and were those themes that described influences that had, or would, precipitate seeking help from formal services. Formal care utilization themes described how the women used formal services and their experiences with those services and answered the second research question.

*Decision Making Themes.* Themes regarding decisions to seek formal care services demonstrated cultural values of independence, self-reliance, hardiness, family-orientation, and loyalty. These themes werethe following:

- anticipating possibilities,
- doing what is needed,
- listening to and valuing the views of others and
- seeing no other choice.

A brief description of each decision making theme and exemplars follow.

*Anticipating possibilities.* While the study participants were independently living in the present moment and caring for themselves at home, they had used formal care, on occasion in the past and knew that they might have to do so in the future, given their advancing years and health problems. They therefore, anticipated, or expected future use of

services. This "anticipating possibilities" is exemplified by the following statement of a woman who at the time of the interview had no primary care provider: "I'm gonna hunt me a doctor 'cause I'll need one before long, maybe later."

*Doing what is needed*. Health services were not used by these women on a regular basis. The women were basically self-reliant and use was episodic when a need arose. Few of the women practiced preventative screening. The majority of the women (*n*=11) reported not having regular yearly check-ups. Two women reported having yearly mammograms, and only one reported a pap test within the past year. One woman stated:

> I don't go on a regular basis to see about anything. I don't know how soon I might have to, might need to, I don't know when that will come.

Often the decision to seek care was precipitated by situations where there was a specific need that only formal care services could meet. Further, the women were quite hardy and independent and would frequently put off seeking care until the need was severe. They delayed formal care and used it only to get what they perceived they needed, rather than have regular health screenings or preventative care. An example is the following:

> I had my upper teeth pulled up here, at the other dentist. That's been years ago. I've got an upper plate. But, I've got a few bulges that are in bad shape, but I guess I'll keep them unless they get hurtin' so bad I can't stand it.

When the same woman was asked if she would go to the clinic if she got sick, she replied, "I don't go there unless I have to." Another woman said that she would "go to the doctor when you need to go." Some of the needs included "pretty sick," "ran out of medicine," and "getting low on medicine." Another woman stated, "I go once in a while for a check up so I can get the medicine. You can't get it if you don't."

*Listening to and valuing the views of others.* The women in this study would seek services if they were given advice to do so by family members demonstrating the cultural value of family-orientation. They would also

listen to others whom they considered "experts." In many cases participants spoke about family members pushing them to go to a doctor. Because the women wished to please family members, they would seek services. One participant stated:

> My daughter, she came in and wanted me checked out. Yeah, she did. She said 'I'm going to take you to a doctor' and I'm willing to go through everything for her.

In another situation a participant sought help for her chest pains when a man who had experienced heart problems suggested that she go.

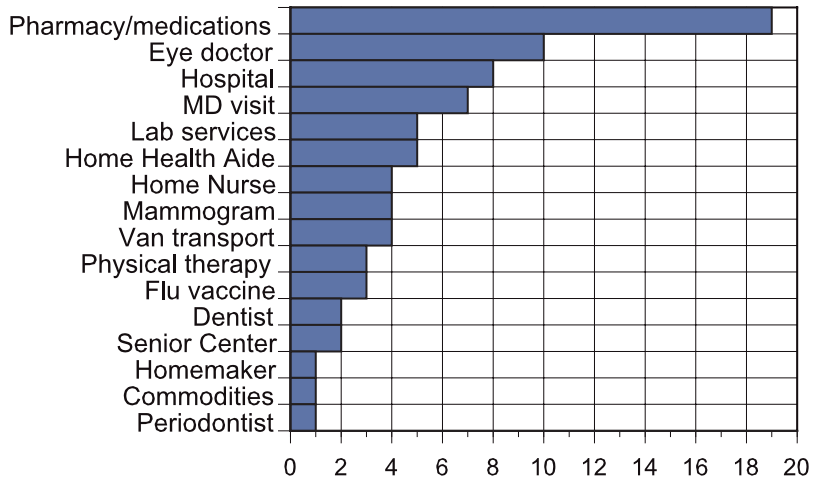
> This fella that had had a lot of heart problems came over and sat down with us.... we were over there getting our coffee ordered and he came over and sat down and talked a little while. He looked at me and said, 'What's wrong with you?' I said 'Well, I don't know. I'm having some chest pains or something.' I says, 'I can't hardly breathe.' He says 'You're just about ready to have a heart attack.' Cause he knew, he's, he's one that's real bad off right now. And he knows what it is to be on the verge of having a heart attack. He said 'You're going to have a heart attack if you don't get something done pretty soon.'

*Seeing no other choice.* When an emergency occurred, the women sought help from formal care because they did not see any other option. During these episodes, traditional values of independence, self-reliance and resourcefulness had to be set aside. One participant stated: "I don't like going to doctors. Of course, when I break bones, I have to." The same participant would only seek home health care "if I was down in the bed and couldn't do nothin' for myself." All the women stated that they would seek services in emergency situations.

*Formal care utilization themes.* Formal care utilization themes described the actual experiences that the women had with services or service providers. Themes included "Using on my terms," "dealing with barriers," and "meeting a need." Actual formal care services used included: care provided by physicians, nurses, optometrists, hearing aid specialists, home health care personnel, pharmacists, and therapists; care provided in hospitals, clinics, or the home; pharmacological use; community

health services used, such as health screening services and influenza vaccinations; use of senior access vans and senior centers; and assistance provided by commodity distribution centers or other financial assistance programs. See Figure 1 for an illustration of specific service utilization. A brief description of these themes and exemplars follows.

**Figure 1.**
**Number of Women Using Formal Services by Type (Past year)**




*"Using on my terms."* The women in this study not only sought formal care services on their own terms, but also used the services and resources that were provided on their own terms, that is, in their own way and in their own time demonstrating their independence, self-reliance, and resourcefulness. Particularly in the case of health care services, the women themselves made the decision to seek a service, contacted the service when they were ready, and then chose to utilize or not utilize all or part of the treatment regimen prescribed or suggested. As one woman related regarding the physician's suggestion to take an aspirin daily:

> I reckon it uh, gets my blood too thin if I take 'em every day. They want me to take 'em every day but, just uh, sometimes I skip two or three days and stretched it.

Many women in this study also

selectively chose services offered by senior centers. Although they could receive meals there, many did not feel the need to take meals at the centers as long as they were able to cook for themselves. One woman expressed this lack of need:

> I go down to the senior citizens, we always eat lunch and then I take exercise before I eat, and uh, I sometimes go back after I've had my lunch and we are there to lunch. But uh, I don't uh, I don't really, I mean I don't feel the need for that as long as I can fix things for myself.

One woman was told by her physician that she had gall stones and needed surgery, but she elected not to have the surgery because she did not have the time and she didn't believe the diagnosis:

> ...and I was making garden and somebody called up here, it was one of the ladies and she said that uh, that Dr. T. was in touch with them and you need to make an appointment to have surgery. I said I didn't have time for surgery. I'm making a garden and I have not been back to the doctor.

*Dealing with barriers.* The largest theme of formal care utilization describing the experiences of these women was "dealing with barriers." These women met with difficulties in obtaining and seeking formal care services. The barriers that the women dealt with were both internal and external. Utilizing formal services often threatened to change past patterns or were in opposition to cultural values and was difficult for these women. One woman had to have home care services in order to continue to live at home, but this created conflict for her because she did not like "strangers" in her home. Some women faced problems with keeping the same physician or dentist that they had used for many years. They were very loyal to trusted service providers. If providers moved, the women would travel long distances, if able, rather than change. When travel was not feasible, or if the provider retired or died, these women often hesitated to seek care from a new, unfamiliar provider, particularly if these persons were viewed as "outsiders." One woman summarized this attitude:

> The ones at the clinic are from Egypt or from somewhere else. They all have dark skin like the Mexicans. People here are funny. They trust fellow hillbillies and they don't trust people like that.

The women in this study also related stories of inability or difficulty in getting formal services or access to care. One difficulty was the high cost of medication and care. Women who were taking a number of medications or particularly expensive medications and had limited incomes especially voiced this concern. Sometimes medication was not taken because of lack of funds. One woman who was hypertensive related:

> I got a nurse that comes to see me every week and she said it was up just a little bit, but I was out of my medicine that I'd been used to taking and I hadn't been able to get.

Another problem was the distance necessary to travel to health care providers. Some of the women did not drive and had to rely on relatives or others for transportation. Others drove, but only locally and were reluctant to drive distances or to unfamiliar cities.

Perceived lack of caring by health care providers was another problem experienced when accessing formal care services. There were several stories of being devalued and ignored when the women sought formal care services. Situations were related where symptoms were ignored and major medical problems such as heart attack and fractures were later found. These encounters left the women feeling frustrated, angry, and mistrustful of formal care providers. One woman aptly related:

> I have some sharp pains ever once in a while. I told the doctor. I got so aggravated with him after my surgery. I was really concerned and I kept on asking him. I said 'Why do I get so sore up here?' He didn't pay any more attention to me as if I would a been a bug out yonder on the post somewhere. And I got fed up with it. I thought, I hurt in there and I don't know why. I mentioned it to him time after time.

Encountering difficulties in accessing or seeking formal services or problems with service providers resulted in inability to fully utilize needed services or distrust of the formal service system.

*Meeting a need*. Utilizing services often resulted in having needs met, namely the need to remain in the home, the need to remain or regain function, and also transportation needs. Several of the women had used home health care services for a limited time after surgery or injury and related that the care they received from these services was very useful and allowed them to come home rather than going to a nursing home. The one woman who was receiving home health and homemaker services on a regular basis credited these services with keeping her at home and relatively independent stating:

> Well yes, I get some help. I couldn't stay here if I didn't get some help. I like living by myself for one thing. Which I don't have any other choice either, unless I went into the nursing home and I don't want to have to do that until I absolutely have to."

Many women related that when they really needed medical care, the medication, physician, surgery, or therapy restored their health and functioning and allowed them to continue to live and function in their homes. One woman who injured her arm and received home health care related:

> ...my doctor had the health, the home health nurses to come when I had my arm. It was that bad...It was fine. They'd take my blood pressure. Then they taught me how ta' exercise. that's one of the best things that I ... Yeah, I can wake up in the night with this leg hurtin,' and I can get up and do some of those exercises and I can go back to bed and go back to sleep.

Getting around was an essential need for nine of the women who did not drive. This need was met for several women through use of a senior van. Stories were related of van use to go to doctor appointments, get medication or groceries, or go to senior center activities. There was general satisfaction with the use of this transportation service. The drivers were perceived as being pleasant and accommodating. One woman related:

> Yeah, we have our own van, and the driver's a boy, a man I worked with out at B. and he fusses from (the) time I, blows real loud for me to come. He knows I'm comin' but he like to pick on me (laughs)."

Utilizing formal care services assisted the women in this study to remain in their own homes, regain or remain function, and get out to important doctor appoints, run errands, and socialize at senior centers. The women recognized the importance of these services in keeping them in their homes and were generally either satisfied with the services or recognized that the services were needed.

## Discussion

This study supported previous findings that older women continue to live independently, even with limitations in functional health.[51,55] Despite research documenting that older, rural Appalachian women have significant risk factors for leading causes of mortality,[56] findings from this study support previous research findings of low use of screening mammography and Pap tests in rural, poor, or older women.[9] In addition, this study supported findings of Barnes and Berg-Klug[5] that in addition to low income, lack of transportation, geographic isolation, and dearth of health care providers in rural areas constitute barriers to obtaining appropriate health services.

This study demonstrated that even when resources were available, cultural values, attitudes and beliefs, including mistrust of strangers, independence, pride, hardiness, loyalty, family-orientation and self-reliance were found to constitute significant barriers to use of services, answering research question one. These findings also support Leininger's[52] theory of the importance of cultural influences regarding decisions on use of formal system services.

Experiences of the women with formal services were richly described to answer research question two. Stories of these experiences demonstrated the influence of cultural values and beliefs of independence, self-reliance, resourcefulness and hardiness in the theme "using on my terms" and the influence of the values of loyalty and independence as well as mistrust of strangers as internal barriers when obtaining services. Cost and distance were also barriers. Further, experiences were related that were characterized by lack of respectful, empathic approaches by health care providers and poor

communication. These experiences created an environment of mistrust that resulted in less utilization of available services. However, the women related that utilization of services did meet a need and allowed them to continue living in their homes. Therefore, the experiences were positive in helping these women maintain independence and successfully age in place.

One of the greatest challenges facing health care delivery systems is that of working with diverse ethnic populations. There need to be specific culturally sensitive approaches based on cultural values and regional influences to serve individuals and communities.[57-58] To meet this challenge health care providers must be knowledgeable and incorporate these cultural values into culture-specific interventions. Physicians, nurses, social workers, home health aides, and other healthcare providers need culturally specific health information in order to offer culturally congruent health interventions and health promotion behaviors.[59]

It is important for nurse providers, educators, and researchers to recognize cultural influences on health and service utilization decision-making. The older Appalachian women in this study valued independence and control over their lives. Any approach to health care services for this population must take this into consideration. These women must be active participants in their own health care decision-making. These women also distrusted care providers who were not “fellow hillbillies.” Care providers who are “insiders” such as Parish Nurses, or community raised local clinic nurses would obviously be more acceptable to these women. Recruitment and education of nurses, physicians, and other care providers from these rural areas and encouragement for return to practice in these areas is needed.

Treatment regimens also must be congruent with cultural lifestyles and belief systems for these regimens to be accepted by rural elderly women. Client teaching should incorporate and recognize existing patterns of living, such as life styles that include gardening and canning. Finally, it is essential that the client-provider relationship be one of mutual respect and trust, with care providers actively listening to and

valuing input from clients.

This study has highlighted the need for further research on health care service use by older rural Appalachian women. The generalizability of the findings is limited by the small sample size. Further research is needed in other Appalachian counties and studies are needed with larger sample sizes. This study also focused on Caucasian older women. No published studies were found that addressed health care issues of African American Appalachian women, an area that is important to explore. Understanding of these women's care systems is the first step in assisting nurse care providers to plan new culturally sensitive health delivery models.

Two overarching goals of *Healthy People 2010*[60] are to: a) increase quality and years of healthy life, and b) to eliminate health disparities. Included in quality of life are health, recreation, culture, rights, values, beliefs, aspirations, and conditions that support a life that contains those elements. Rural older adults, such as the older Appalachian women in this study, face challenges of geographic location, higher poverty levels, lack of resources, and physiologic decline.[61] These factors all contribute to health disparities in this population.

Need for formal care services increases in aging populations. Community wide efforts to promote healthy behaviors, create healthy environments, and increase access to high quality health care are important in meeting *Healthy People 2010* goals. Interventions that assist Appalachian elders with appropriate utilization of community resources can enable those elders to remain functional within home and community environments, improve their quality of life and reduce the burden on acute and long term care facilities and rural communities.

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