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Priorities for Action in a Rural Older Adults Study

Jennifer B. Averill, PhD, RN
College of Nursing, University of New Mexico, Albuquerque

Abstract

This article reports the findings from a recent study of older adults in the rural southwestern United States and discusses practice and research implications. The aim of the study was to analyze health disparities and strengths in the contexts of rurality, aging, a depressed economy, and limited health resources. Identified themes needing action included sustained access to prescriptions, transportation solutions for older adults in isolated communities, inadequate access to care, poor infrastructure and coordination of services, scarce assisted living and in-home care for frail older adults, and barriers related to culture, language, and economics.

Keywords

community-based participatory research; community and public health; critical ethnography; cross-cultural nursing; health disparities; rural older adults; social networks

The Healthy People 2020 objectives call for more long-term services, support for older adults and their caregivers, increased preventive services, and effective management of chronic conditions for older adults in rural and urban settings.[1] Approximately 20% of Americans, or 55 million people, currently live in rural communities with fewer than 2500 residents. In general, rural populations experience higher rates of heart disease, cancer, injury-related deaths, diabetes, and depression than do urban populations. Rural communities are also characterized by lower rates of personal income, educational attainment, health insurance coverage, access to emergency and specialty care services, and reported health status of adults than are urban communities.[2–4] Data are scarce regarding the perspectives of rural older adults in New Mexico, a culturally diverse state, with the third highest poverty level among states and a statewide poverty rate of 18.1%.[5] Even less is known about the health care perceptions, experiences, and contextual issues of rural older adults in southwestern New Mexico on the US-Mexican border, afflicted by the decline of the copper mining industry and struggling to meet the needs of successful aging in place.

Deeper understanding of these collective perceptions, social determinants, and contexts of health emerged from an examination of the social ties and networks that characterize the rural communities, linking all stakeholders, especially regarding older adults. These networks were analyzed in the context of overall findings, informed by the ideas summarized in the Table.

Building on findings from a pilot study, this current qualitative study analyzed health disparities and strengths in the contexts of rurality, aging, a depressed economy, geographic

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Correspondence: Jennifer B. Averill, PhD, RN, College of Nursing, MSC09 5350, 1 University of New Mexico, Albuquerque, NM 87131 (javerill@salud.unm.edu).

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isolation, cultural tensions, and limited resources for health and social services among multicultural rural older adults in 3 counties in the southwestern United States. The focus was on the older adults perspectives and perceptions of health and health disparities, in their own words. This article reports the findings from the study and suggests implications for practice and research initiatives.

The pilot study was smaller, encompassed one large rural county in the same study area, and utilized the same methods as the study reported here. Results showed that participants' definitions of health varied with socioeconomic status and included avoidance of contact with the health care system, obtaining needed medications, remaining independent, a sense of spiritual belonging, eating wisely, and exercising moderately. Older adults identified the major concerns of escalating prescription costs, inadequate access to care, and social isolation.[17] However, existing strengths and assets were also identified: older adults knowledge about sustaining health in austere conditions and caring for the sick using simple measures; an existing group of dedicated professional providers applying their best efforts and knowledge to the challenge of health care; and a preexisting community-based action group working to decrease fragmentation of services, streamline delivery of services, and work with legislators on funding priorities.[18] Rural studies in other settings have identified similar findings, with some regional and cultural variations.[4,19,20–27] However, variations in cultural groups, patterns of immigration/migration, impact of specific local politics and economies, available resources, and the particular social networks in play result in important differences among rural settings. It cannot be assumed that all are the same, and no work has been documented about the health-related perceptions of this group of multicultural older adults.

CONCEPTUAL FOUNDATION

The theoretical background for this study drew strongly from community-based participatory research (CBPR), which may be interpreted as both a theoretical approach to research and a set of specific strategies for conducting investigations. The participatory sequence formulated by Stringer of *Looking*, *Thinking*, and *Acting* was used.[19,28,29] Each step of Stringer's sequence corresponds to a key research phase of this work. The completed study can be characterized primarily as *Looking*: recognizing, gathering, defining, and *describing* the situation. The next phase will move beyond description to frame the quantitative constructs, measures, and models that are critical to the *Thinking* phase, which is more focused on *explanation* than description. Out of *Looking* and *Thinking* come *Acting*, and this phase will correspond to a large, definitive evaluation, to be submitted as a future intervention project, targeting the interventions and services identified in the upcoming *Thinking* phase.

DESIGN AND METHODS

Critical ethnography and CBPR

The study design blended critical ethnography and CBPR. Critical ethnography combines descriptive ethnography, communicative interaction, and critical analysis of contextual factors,[30,31] as well as strategies commonly used in CBPR.[32,33] The focus was on the discovery, interpretation, and translation/application of *local knowledge* to practice, rather than on testing hypotheses. Community residents were the experts in the description, analysis, and interpretation of their own cultures, lifestyles, and ways of engaging the health care system, public or private.

Critical ethnography and CBPR echo what Denzin and Lincoln[34] refer to as "the merger of indigenous [local] and critical methodologies"(p2) with the essential attributes of ethical

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inquiry, respectful engagement, transformative potential for inequities, and direct pertinence to the needs of the community. On the basis of a dialogue and partnership between the researcher and community members/participants throughout all research activities, CBPR was a natural extension of critical ethnography, the intent of which was to identify, analyze, and resolve important health or social problems.[35–37]

Sample and setting

Consistent with CBPR principles, a subset of interested key informants in each county made up the community advisory board (CAB) for the project. The CAB followed all phases of research, asked questions, and responded to questions from me. Working through the CAB, using purposive sampling[28] of private and public health care organizations, the study included 64 participants across 3 rural counties (12 men and 52 women). Fourteen women and 5 men self-identified as Hispanic, and 38 women and 7 men self-identified as non-Hispanic whites. Of the 64 participants, 40 were 65 years or older. The remaining 24 informants were adult family members, providers, or other community-dwelling adults who in some way influenced the health care system (public or private) for rural older adults groups. Although I attempted to include a sample that represented the demographic profile of the region, my final sample did not completely match the approximately 50:50 split between Hispanics and non-Hispanics in the local demographics, possibly because larger numbers of Hispanic residents were difficult to reach through the contacts that I used in the study and because few providers and other agency personnel were Hispanic. It was not possible to precisely document differences in poverty levels between men and women in the study region, but sources have noted that women usually make up 65% of the rural poor at least 65 years of age; widowed women are even more likely to be poor than married women.[19,29] In the state of New Mexico, 16% of all persons 65 years or older live in poverty, compared with 14% nationwide. In terms of age, 24% of all females and 22% of all males in the state live in poverty, compared with 20% and 18% nationally, respectively.[38]

The older adults in this study diverged into 2 major groups: (1) individuals who were born in the region, who had lived and worked locally all their lives (having been mine workers, ranchers or ranch hands, farmers, or railroad workers), and who averaged 4 to 7 years of education (with just 2–3 individuals who had graduated from high school or a local college); and (2) retirees from elsewhere in the United States, who came to the region because of its mild climate, lower cost of living, and nearly constant access to outdoor adventures.

Though widely dispersed, the counties were all located in a region of high desert and mountainous terrain, with few major highways, 4 definitive seasons, and significant distances between towns or cities. In fact, major cities were no closer than 80 miles away in 1 county and even further in the remaining 2 counties. I selected the 3 counties on the basis of distinctive features of demographics, history, and settlement patterns to note similarities and differences in health care challenges. The immense geographic area and the scarcity of large population centers directly impacted the capacity of older adults to obtain needed services.

Procedures

Specific methods used for this study were establishment of trust with public and private sector agencies, ethnographic fieldwork and interviews (one-to-one and in groups), field notes and a reflective journal, participant observation, photography, and archival review. Approval was granted for this study by the University of New Mexico Health Sciences Center's institutional review board, and all data were collected with signed, informed consent forms from participants.

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Establishment of trust with stakeholders—Having previously learned of the region's geographic, demographic, and socioeconomic features,[39] I spent 3 to 5 days in each county prior to data collection, connecting with key stakeholders. The stakeholders represented public and private organizations, including managers, providers, and key personnel in hospitals, home health and hospice agencies, senior meal sites, administrative offices, and local groups (community health councils, volunteer centers, and colleges with health care programs). These contacts were gatekeepers for the older adults and directed me to participants for subsequent interviews. I met with the CAB each time I visited the region.

Ethnographic fieldwork and interviews—Ethnographic interviews were the centerpiece of data generation, taking place in homes, agencies, clinics, senior meal sites, and even automobiles. I asked a combination of open-ended, descriptive, structural, and contrast questions.[40,41] I queried older adults for their definitions of health and perceptions about health care experiences with providers, services, and facilities; specific issues or problems that concerned them about health care for rural older adults; strategies for managing health care dilemmas and challenges; strengths, resources, and barriers existing in the present system; what else was important to them that we had not yet thought to ask; and (supporting CBPR) how they would like to see the information get used in their communities.

English was the language of choice for most informants, although a translator was required for several interviews. Most of the interviews were tape-recorded and later transcribed or were documented in field notes when individuals preferred not to be audiotaped.

Field notes and reflective journal—Field notes captured the daily activities, communications, and encounters in a log, tracking dates, times, types of actions, miles traveled, and specific sites (agencies, homes, communities or towns, centers, libraries, and stores). For interviews where the participant did not want to be audiotaped, the notes contained my summary and synthesis of key points in the discussion.[42] Simultaneously, I kept a reflective journal that allowed me to explore dilemmas, problems, unanswered questions, emerging ideas, potential topics for future interviews, and deeper levels of insight and awareness about the overall study.[43]

Participant observation, photography, and archival review—Honoring ethnographic traditions, work as a participant observer allowed me to live briefly in the daily lives of participants.[36] I joined them for meals; went with them to appointments; sat with them as case workers, nurses, and others performed assessments and evaluations; and visited them in their homes, neighborhoods, and senior centers.

Adding a visual component through photography forged the conceptual link for "real-world contexts to understand how culture impacts on cognition."[44] The pictures of older adults and settings depicted a more detailed and personal portrait of the older adults for care providers, planners, and policy makers who influence the resolution of health disparities in rural settings.[44–46]

I reviewed and documented archival data, such as historical records at local libraries (to note past cultural and settlement/migratory patterns); eligibility brochures and pamphlets at local agencies (noting readability levels, language options, and financial requirements); local newspapers (to see trends in *public voice* when analyzing health care and other services for rural older adults); and Web site information presented by various community groups. These data were part of the contextual scene for the older adults and constituted an important dimension of the total picture.

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Data analysis

Procedures used to analyze the data included sequential coding, thematic analysis, matrix analysis, and strategies for methodologic rigor. Although not a linear process, the fundamental actions for analysis of the interview data, field notes, and researcher's journal are summarized as follows[40]: (1) detailed reading and open coding of the transcripts; (2) resorting of the identified segments into distinct conceptual categories for additional analysis of commonly coded portions, or secondary coding, yielding a final set of codes common across all data; and (3) synthesis and integration of the recurrent patterns, emergent across all of the data, into distinct themes, or propositional statements/linkages among codes/ patterns.[40,41]

Congruent with the philosophies of critical ethnography, CBPR, and public health nursing, I applied 5 criteria for study integrity and quality[47–51]: *transparency, partnership, precision, evidence,* and *compassion. Transparency* refers to clarity, auditability, and ease of seeing, following, exploring, and querying research activities for all stakeholders. *Partnership* refers to a condition of consistent collaboration with community advisors in a joint effort and being community engaged in all phases of work. *Precision* refers to practice of exactness, accuracy, correctness, and care in all details of research design and process, with attention to all phases of action and interaction. *Evidence* means anything that presents as useful data (empirical, aesthetic, political, etc), such as documents, measurements, artifacts, art works, objects, clues, substantiation, and signs/indicators. *Compassion* refers to consistent benevolence, empathy, humanness/humanity, civility, patience, kindness, and acts of conscience for all concerned.

The criteria were achieved by (1) efforts to check the findings against contradictory evidence and explore for variations throughout all phases of the inquiry[28,41]; and (2) the overarching idea that research should reflect empathic, compassionate relationships with respondents; community-centered dialogue; professional, personal, and political commitment in support of change and equity; and an orientation to human caring ethics.[48,50,52]

RESULTS

Key themes and definitive issues for action identified by the older adults included (1) the need to consistently manage prescription costs; (2) gaps in transportation between isolated communities and health care resources; (3) inadequate access to primary and specialty care; (4) poor social infrastructure and coordination of services; (5) scarce assisted living and in-home care for frail older adults; and (6) barriers related to culture, language, and economics. Literature addressing problems for older adults in all settings, both above and below the poverty level, suggests that the issues identified here are not unique to the rural southwest. However, the severity of health disparities, access, transportation, and other barriers is greater in geographically isolated, economically poor settings, such as the rural counties in this study.[1–5,19,20–23]

Community assets were also identified, including (1) local health councils, (2) volunteer groups, and (3) a regional medical center in 1 county. Again, themes generally resembled findings from other rural health studies,[2,20–23,33,53] yet manifested in unique ways because of the geographic location, a particular blend of cultures, and the economics of the southwestern US-border region. The themes also supported evidence presented in Healthy People 2020, Institute of Medicine (IOM) reports on rural health, and the National Rural Health Association, regarding the most challenging problems for community-dwelling rural older adults.[1,3,20,24,26]

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Affording and maintaining prescriptions

Given that the median age of community residents in the region continues to rise, that income levels for all residents tend to be lower than the national average, and that older people generally have multiple chronic conditions, managing prescription expenses was a major concern. People told stories of having to choose among groceries, rent, or a prescription. In addition, many of the older people, especially those 80 years and older, did not drive because of lost vision, mobility, ability to afford a car, and/or the service of nearby relatives to drive them. Participants told me that they routinely skipped medications, cut them in half, or went without, using instead a variety of home remedies (eg, drinking more water, taking herbs, eating certain foods, or practicing a ritual of prayer) to manage their symptoms and diseases.

Respondent voices echoed this theme in their own words. According to a senior volunteer who helped bring a grant-funded medication assistance program to homebound older adults, “We’re not hitting all the people who need this help [for obtaining their medications]. Some don’t return, can’t do the paperwork, or don’t reapply after the 3 months. So some aren’t getting what they should to be healthy.” A retired elementary school teacher told me, “My friends all go to Mexico for it [medicines].” A homebound, wheelchair-bound older woman who depended on others for her groceries, medications, and other services said, “I know what they mean when they say, well, this month I’ll buy the medicine, I guess I won’t next month …. If I have enough for my medicine, I get lower foods or no food.” A man who cared for his seriously ill wife alone added, “Well, we have our troubles, and uh, the distance to go for it [their prescriptions] is too much, so we just don’t do it.” And, finally, from an older adult who also participated as a member of the local health council: “The whole thing for drugs is hard. They didn’t have co-pays before, and now they’re paying 10 bucks. That’s a lot harder and it’s a lot to pay when you’re on a fixed income.”

Transportation gaps

In a region dominated by great distances between towns, providers’ offices, and other sources of health and social services, families have been separated by economic hard times and the need to find work at a distance from home. An informant who directed a large public agency commented,

> For some older people … they’re either too old to drive or not safe to drive, even if they have a driver’s license. I don’t know if I want them out on the streets and roads. If they have a license and they’re safe, they usually don’t have a car.

A locally funded senior transport van briefly served several of the larger rural towns. However, eligibility requirements excluded people living a long distance from the towns. In addition, physical capacity to be ambulatory and go to pick-up points, available time for drivers to assist people who required more help, and costs passed on to van users limited access to transportation. A lay health worker observed:

> People have told me they often miss their appointments because they [van drivers] are never there on time, or they don’t give ‘em enough time to make it to the appointment on time to see the doctor. And then they have to pay 5 bucks or 7 bucks to use the van. They don’t have it.

Care access

Care access problems for older adults usually involved too few primary care providers and specialty providers; providers who could not speak the language the older adults spoke; and/or providers who left before establishing meaningful relationships with them. According to a retired participant who also worked as a senior volunteer, “I do think people fall through the

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cracks to the tracks. A large number don't have medical coverage or even get medical attention or dental care, eye care, or prescriptions at all."

There were exceptions to the overall findings because some retirees entering the region lived in the more populous communities, closer to providers and necessary services. For the most part, this retiree group held higher educational attainment than locals who had worked in mining and agriculture, were more likely to have supplemental health and prescription insurance, and were more likely to gather in large social groups at senior centers, community-based activities, and planned recreational activities. However, a care provider for a home health agency commented,

> We see too many of these older couples move out here from wherever. They do okay for a few years. Then one of them either dies or gets real sick, and their families are far away. It leaves the other one alone. They don't know the doctors here, or they don't like the ones who talk with an accent. And they don't know what to do, where to go. But they can't seem to get into the idea of finding a primary provider and getting referrals, especially into hospice. Sometimes they are too afraid. They don't trust people, they don't have extra insurance, and sometimes they even die alone at home.

Thus, an unanticipated finding was the growing need for palliative care and assisted living options so that people could remain at home for life.

Patchwork service network

During the study, it became obvious that work was needed to accurately document exactly which agencies offered what services; what the various eligibility requirements were; what funding sources supported the programs; what kind of strategic planning, if any, had occurred to keep programs sustainable into the future; what plans existed for linking to other services and programs in the region; how specific information about health and social services would be disseminated, communicated, assessed for adequacy, evaluated for effectiveness, and revised in response to analysis and critique; and how the necessary personnel levels could be maintained or expanded. Consultations with the CAB supported these impressions. As one older adult council member commented, "Sometimes our right hand doesn't know what the left one is up to."

At times, the stories were quite sad, like the one told by a long-time home care nurse:

> We had a patient, she lived alone in the mountains east of town. She'd been sent home from the hospital and we could not get to her for a week, with holidays and the weather. When I finally could go, we found her dead in a tub of water. She tried to give herself a bath, nobody was there to help her, and she died. We don't know if she had a heart attack or what.

In another case, a public agency charged with coordinating a network of federally funded senior services had just 1 lay caseworker for an enormous service area. Bicultural and bilingual, she was responsible for performing all intake and follow-up assessments on homebound seniors receiving services through that office. She commented, "I see a lot of old people who could use wheelchairs, ramps, and bars in their homes. But there's no way to get them there. And some live pretty far away from town, you know."

Scarce assisted living options

Throughout the study and since its completion, the need for assisted living options has grown as a theme for residents and research partners. With a swelling older population, the need for affordable housing expands. In part because of the depressed local economies,

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scarce opportunities exist for either institutional assisted living or aging-in-place and at-home care alternatives. An older adult who lived alone said, “There’s this homeless grandmother and grandfather around. They get sick and don’t have a place to go.”

Interviews with care managers, care providers, agency administrators, senior volunteers, community health councils, and other informants from the various senior centers revealed the greatest gap in senior care to be for those who need help with activities of daily living, meal preparation, symptom management, and medication regimens. A manager of a local senior center noted, “There’s this huge need for something in between, you know, retirement housing or assisted living, or even hospice. Places people can go that are not nursing homes. And most long-term places are full and not open to admissions.”

Nationally, Hawes and colleagues[24] proposed that assisted living as it is currently implemented in the Unites States is likely not to serve the needs of frail rural older adults. Byok and colleagues[53] found that in New Hampshire, citizen forums on the need for palliative care argued in favor of more services in rural areas and requested that more research funding be set aside for this topic. A long-time home care nurse in my study remarked, “We see people who shouldn’t even be in the home, don’t have any family here, but we can’t get them placed in a long-term care facility, and the hospital won’t take ‘em ‘cause they’re not really acute.” Since the National Institute of Nursing Research invites proposals on palliative and end-of-life care, this finding represents a potentially valuable opportunity for rural health researchers to influence community-based care for rural older adults.

Barriers of culture, language, and economics

For older residents of these rural communities, often lacking adequate health insurance coverage, prescription benefits, educational attainment, health literacy in any language, capacity to adjust to the fast pace of busy health care centers and clinics, patience with impatient others (office staff, assistants, and health care providers), and persistence to keep pushing for what is needed, their situation has become dangerous, disconnected from care and advocacy, and so unpleasant that avoidance becomes the strategy of choice. In fact, when I asked what people considered the key definition of health and staying healthy, they overwhelmingly responded, “Avoiding contact with the health care system!”

Barriers to care exist around cultural misunderstandings, language deficiencies of both patients and providers, and the economics of purchasing health care, prescriptions, and other related services. The values of each distinct group are based on their birthplaces, the socioeconomic status of their own and similar families, experiences of their parents and ancestors, immigration patterns in respective generations, and the roles they have held in local society and community life. At one senior center, I noted strong differences between some of the native-born Hispanic older adults and the ones who migrated from Mexico in the last 20 years. A Hispanic woman born in the region more than 80 years ago said, “Those people from Mexico are not like us. And they don’t think like us, we don’t like them very much, but they’re here.”

Letting go of earlier norms when providers knew all the families and treated them as additional family members is difficult for people in their twilight years, especially when they perceive that no one cares who they are, what they think, or how they truly feel. In the words of one informant, “It’s just hurry up, tell me what’s wrong, and pay before you go.” At a meal site in a former mining town, a group of miners’ widows sat together for their daily lunches and traded stories about how each one was getting along. One of them said, “We pretty much do for ourselves, and we don’t need much help. Anyhow, they [health care providers in their region] don’t know us any-more.”

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In addition, English has always been a second language for some residents, and if they attained less than a high school level of education, they suffer frustration at the inability to either understand or discuss a complex health problem—a striking example of health literacy deficits. Many of the providers speak only English or have come from another country, speaking neither English nor Spanish clearly enough for the older adults to understand. Thus, it was not unusual to hear people say that the providers “never understand me, and I don’t understand what they are saying.” These findings resemble results obtained by Torres,[25] Borders,[26] and Guo and Phillips[22] involving other Hispanic populations.

Economically, many older adults have spent their lifetimes being frugal because they never earned enough money to generate savings and were raised to value saving whatever income they earned. They have little to spend and are reluctant to spend for things they consider minimally helpful. Complicating matters is the lack of case managers or navigators for both public and private organizations, limiting use of agencies and fragmented services. One informant said,

> If you look at access, as they get older, the access to care is going down. And especially among Hispanics, who are about 50% of our population. We’re not sure why. Maybe some have no extra money or don’t like the way appointments work these days, or just feel uncomfortable getting out of their homes.

The manager of a publicly funded health service stated, “Sometimes, older people put off health care—it’s a change in personal and family culture to use preventive services.”

Assets and strengths

Although the challenges to even basic care for the older adults are considerable, rural communities displayed impressive strengths and assets alongside the problems. A closer look at the assets is warranted because before designing solutions, an inventory of what is and is not working well should take place. The strengths will play a key role in interventions aimed at reducing or eliminating inequities. The assets could be summarized as (1) individual peers, family members, and caregivers/providers; (2) community-wide advocacy groups and centers; and (3) an array of rural values that inform the older adults behavior, outlook, and belief systems.

For older adults living alone, select individuals comprised the lifeline and human connection in daily survival. Examples of these individual contacts included peers who lived close enough to visit by walking or watching out their windows, family members who lived with an older adult or nearby, neighbors who had known the older person for a long time, a visiting nurse, a case worker, a social worker, a priest, or a local police officer on patrol. If available, such visitors were often the only source of contact with the outside world, asking such simple questions as “How are you doing?” or “Have you eaten today?” A visitor might notice a new health problem, a lack of available food or heat, a need for home repair, or simply a need for human contact.

Importantly, the presence of a small dog or cat was often the most treasured asset in the daily life of an older person. On more than one occasion, I heard someone say of his or her pet, “If it weren’t for him [her], I’d have nobody to talk to or love.” The pets were family members to them. Without question, this network of both formal and informal individuals was a pivotal asset to a number of rural older adults living alone in the more remote communities.

For each of the 3 counties, at least 1 community-wide advocacy group, senior center, senior meal site, or other organization constituted a helpful asset in terms of health promotion, common voice, or quality of life. One county in the study had an active community health

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council, made up of local residents across the lifespan, representing the interests of all age groups, schools, businesses, health care providers, a local university, a network of senior centers, senior meal sites, a volunteer group, and some faith-based initiatives for assisted living.

Finally, assets and strengths of older residents, regardless of their heritage, culture, or history, nearly always included a set of rural values that infused all areas of their daily life, including the challenges of aging in remote communities. I summarized the core values as resiliency, diligence, autonomy, and spirituality, echoing similar values identified in other rural studies, yet manifest in a way particular to the desert southwest, near an international border.[27] The older adults were *resilient* because in discussing their health, their definitions of health, their view of our health care system, and how they kept themselves active daily, they emphasized that they simply did what they needed to do—get up, get work done, take care of themselves and others, clean up their dwelling, fix meals, stay busy, communicate with people, and remain engaged in the flow of daily life. They spoke of cardiac, endocrine, pulmonary, orthopedic, psychological, economic, family, work-related, transportation-related, and other challenges, but always brought the conversation to the present moment and the fact that they had made it this far, could still handle some things on their own, and planned to do so as long as possible.

Diligence and autonomy were the twin pillars of their approach to daily demands of personal care, chores, attention to family members, pets, and local activities. In the words of a woman who taught school for many years, “We worked every day, and we didn’t take money unless we got it done.” Laziness, inactivity, or refusal to try and do something useful with their waking hours never seemed an option. They made it clear that no one else was responsible for their happiness.

When I asked what was most important to them in their lives and in their aging, they usually responded that some kind of *spiritual* or *religious orientation* was central to health. The majority spoke of a particular church or a daily ritual of prayer, “quiet time to think,” or of simply being outdoors to enjoy nature. The key seemed to be a connection to something larger than themselves and beyond the routines of daily living.

Coaxing from this group of resilient, independent older adults a definition of health proved difficult, because for them, health and how one stays healthy are synonymous. Rather than try and redirect them in terms of language, I allowed them to tell me what mattered most about health and/or staying healthy. Accustomed to a lifetime of daily responsibilities, most participants defined *health* as avoiding the health care system, along with the ability to get out of bed each morning and remain active. One gentleman said, “I hope it don’t get to where I have to live with somebody. I don’t like to be a burden or have somebody tell me what to do.” A retired nurse added, “Health is keeping a good weight, staying active with walking and whatever. And a proper diet. And a spiritual life with daily prayer and meditation.”

LIMITATIONS OF STUDY

While providing rich documentation of participants’ perceptions and ideas, the study had several limitations. As a lone outsider conducting the investigation in a vast rural locale, the researcher likely missed finding additional data sources and informants who might have added breadth and depth to the insight achieved. The trend toward team science will insure that all future investigations will consist of multiple investigators. Also, any outsider will hear and observe only part of the whole picture surrounding the lives and health care dilemmas of community-dwelling older adults. Future studies should include a local

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community member as part of the research team, to increase the likelihood of more complete understanding and data capture.

In addition, the critical ethnographic/CBPR strategy yielded narratives, experiences, and observations that could only happen in sustained fieldwork, with few restrictions on time, distance, or setting to generate the qualitative data. Yet, missing from this study were concurrent opportunities to garner epidemiological or statistical parameters of older adults health that might have strengthened the conclusions and findings. Those data will be planned into future studies in the region.

CONCLUSIONS AND IMPLICATIONS

Practice and research implications are necessarily at the level of the rural community (as opposed to individuals), involving local residents/CAB, agency representatives, and researchers as partners. The implications are that (1) community partners must be multi-disciplinary and multicultural, combining lay, professional, and retired participants; and (2) evaluation criteria will blend researcher participant strategies and mixed research methods in a negotiated effort. Given that this study was exploratory, using critical ethnographic and CBPR methods, it is not feasible to predict with certainty or clarity exactly what interventions or evaluation strategies will be employed in future studies. CBPR requires that when a new phase of work begins, the research team will need to meet with community stakeholders to revisit priorities for action, brainstorm best methods for implementing interventions (blending mixed-methods science with community preferences), analyze limitations and local/cultural considerations, engage in self-reflection on the completed and suggested research/practice, and design a partnership model for all research activities.[30–34,36,37,47,49,50,52,54]

All research aimed at developing specific interventions and actions will necessarily involve the input and partnership among community advisors, advocacy groups, multiple disciplines and professions (from the sectors of health care, business, education, technology, and government), and researchers, a conclusion supported by the IOM.[3] Not only is this kind of multivoiced team-building essential from the perspective of rural communities but also it is increasingly a requirement of national funding agencies. On the basis of findings, emphasis will likely be on care management for older adults across settings, including palliative care in the community and home.

Within the context of community preferences and priorities, interventions should include the guidelines for rural health care suggested by the IOM[3] and Healthy People 2020[1]: greater emphasis on population health; core services in primary care, mental health care, dental care, long-term care, caregiver support services, preventive services, and emergency services; local and regional service links; community voice and engagement in determining services; multidisciplinary and collaborative teams of providers, managers, community members, and leaders; financing options that fit rural communities; and health information technology infrastructure.[3]

Evaluation regarding the merit of any future research will blend both research team perspectives and the viewpoints of community members. As Lincoln[50] observed,

> I label it [research] communitarian because it recognizes that research takes place in, and is addressed to, a community; it is also accurately labeled because of the desire of those who discuss such research to have it serve the purposes of the community in which it was carried out, rather than simply serving the community of knowledge producers and policymakers.(p334)

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As a result, the communities where the work will take place have the authority and support to develop their own criteria for success in upcoming studies.

Finally and importantly, it is important to reprise and examine the importance of *complexity science, social capital, and social networks* as overarching conceptual touchstones in the current program of rural studies. Moving from the general to the more specific observation, I suggest the above ordering of ideas is most plausible as explanatory pattern. The work of Santa Fe Institute scientists such as Waldrop,[6] Kauffman,[7] and others[55,56] posited that humans in all settings tend to organize, collaborate, and pool their resources for solving problems, communicating important information, and meeting challenges. Furthermore, they proposed that the tendency to organize and collaborate for the common good was inherent to individual cells, organisms, people, communities, and systems. Their musings came about after intensive observation, tracing of historical events, interviews/conversations, assessments/tests/modeling of various kinds, and verification over time and multiple data sources. The implications of their arguments center on the interplay of predictability and uncertainty or chaos. Is it possible that the impetus to connect with others is a matter of both physiology and mind, of instinct, motivation, and even survival? Binder and colleagues[57] would argue affirmatively on this point. For investigators studying human communities, implications are that taking time to observe, verify, and document patterns of human actions, interactions, and networks could strengthen the impact of specific/targeted interventions in social health services, business and fiscal negotiations, policy, and politics. This thinking frame resonates with critical ethnography and CBPR, especially as I prepare for next phases of work in partnership with the rural communities.[16]

From complexity theory, it is easy to move into an analysis of *social capital*, an idea central to complex human communities, but with abundant/variable definitions in the literature.[58] Polkinghorne[59] and Bourdieu/Wacquant[60] suggested that human *capital* encompassed at least 4 domains of assets: economic (money, property), cultural (goods, services, education), social (networks, acquaintances, power dynamics), and symbolic (legitimization). I consider all of these dimensions relevant to understanding the rural communities, and study findings provide nascent descriptions of them. Future work should build on these preliminary insights, adding pertinent empirical measurements to better assess our capacity for effective interaction and intervention to help resolve or manage problems for rural older adults.

Abbott cautioned that too often in studies blending surveys with health indicators, investigators try to link social capital with human health in communities.[58] However, often missing in this effort are reliable, valid measures linking the concepts evidentially. He calls for empirical evidence (as opposed to proxy data) to establish conceptual and experiential/actual clarity about *social capital*. If one accepts this notion, then qualitative studies with analyses of the social networks, communication strategies, and effectiveness of partnerships are helpful in establishing operational definitions and accurate metrics for social capital.[12,16] In the current study, I informally assessed the effectiveness, depth, and consistency of partnerships among the community stakeholder groups (eg, senior centers, private hospitals, community health councils, and volunteer groups) and between myself and the various groups to be moderately successful—good in the number of contacts between the individual/group stakeholders and me, the quality of our discussions and problem solving, and in the mutuality of purpose; not as good in consistency over time, capacity to somehow capture, analyze, and leverage the things we collectively learned for future benefit. Although that is imprecise in quantification, it is useful in establishing basic understanding, insight, and knowledge about how human networks operate in the region. It means that in next phases of work, the research team will have a reasonable idea about whom to contact, how to communicate with the various groups, and the best strategies for engagement. I have a decade of work in the region,[17,18] and a few of the current community partners have been

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part of that sustained effort, even as new ones arrived and some departed or died during the interval. Thus, knowing where to start in new stages of work is not a mystery, with specific personal contacts maintained (by telephone, e-mail, and occasional site visits) during and between actual research activities. The aims of this study did not specifically include an analysis of social networks. However, in the spirit of Abbott's[58] suggestions, next studies should include ethnographic data on the *relationships* between social networks and social support (SNSS); social support and reciprocity; SNSS and social capital; and the impact of SNSS on the effects of social capital on health.

Out of complexity science and social/other capital in human communities comes the more specific idea of *social networks*, those webs by which people directly identify, recognize, communicate, and influence daily life, manage stressors for the collective interest, and engage with external entities.[9,11,14] I propose the ideas presented in the Table as key to describing and utilizing social networks. From the macro level of our existence to the micro level of everyday actions and interactions, the social ties people establish, nurture, sever, or otherwise influence are critical to our well-being and ability to survive. Human resilience, hardiness, adaptability, relational capacity, patterns of interaction, and social participation in meaningful activities depend on our social networks—with each other individually, significant others (people and pets), providers of health/social services, community members who help shape political/economic/educational agendas, and even investigators—informal and formal networks make a crucial difference.[8,11–16] Successful social ties appear to strengthen the health, vitality, and quality of life for rural older adults and for others. In this study, the quotations from participants spoke to the role of social networks in keeping people less isolated, more connected to others in their surroundings, and to a greater purpose in their lives. At least one of the stories told of what happens in the absence of such linkages, when someone died alone at home. In a national and local context of scarce economic resources, the social capacity of the communities, especially involving lonely older adults who may not be as mobile as they once were, is critical to their level of health and belonging. Deliberate inclusion of a focus on the nature, quality, and effectiveness of social networks in these rural communities will therefore be intrinsic to future phases of inquiry.

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References

1. HealthyPeople.gov. [Accessed September 3, 2011.] Older adults. http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid#31. Published 2011
2. Glasgow, N.; Johnson, NE.; Morton, LW. Introduction. In: Glasgow, N.; Morton, LW.; Johnson, NE., editors. Critical Issues in Rural Health. Ames, IA: Blackwell Publishing; 2004. p. 3-11.
3. Institute of Medicine. Quality Through Collaboration: The Future of Rural Health. Washington, DC: National Academies Press; 2005.
4. Wright DB. Care in the country: a historical case study of long-term sustainability in 4 rural health centers. Am J Public Health. 2009; 99(9):1612–1618. [PubMed: 19608960]
5. US Census Bureau. [Accessed September 5, 2011.] State rankings—statistical abstract of the United States. Persons below poverty level. 2005. http://www.census.gov/compendia/statab/2007/ranks/rank34.htmPublished 2005
6. Waldrop, MM. Complexity: The Emerging Science at the Edge of Order and Chaos. New York, NY: Simon & Schuster; 1992.
7. Kauffman, S. At Home in the Universe: The Search for the Laws of Self-Organization and Complexity. New York, NY: Oxford University Press; 1995.

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

8. Wheatley, M. Turning to One Another. San Francisco, CA: Berrett-Koehler; 2002.
9. Wheatley, M. [Accessed March 15, 2012.] Are we all in this together?. http://margaretwheatley.com/writing.html. Published 2009
10. Wheatley, M. [Accessed March 15, 2012.] Leadership in the age of complexity: from hero to host. Resurgence Magazine. http://margaretwheatley.com/writing.html. Published 2011
11. Wiles JL, Wild K, Kerse N, Allen RES. Resilience from the point of view of older people: 'there's still life beyond a funny knee'. Soc Sci Med. 2012; 74:416–424. [PubMed: 22204841]
12. Greenhalg, T. Meta-narrative mapping: a new approach to the systematic review of complex evidence. In: Hurwitz, B.; Greenhalg, T.; Skultans, V., editors. Narrative Research in Health and Illness. Malden, MA: Blackwell; 2004. p. 349-381.
13. Kotelchuck R, Lowenstein D, Tobin JN. At the intersection of health, health care and policy. Health Aff. 2011; 30(11):2090–2097.
14. Grbich, C. Qualitative Data Analysis: An Introduction. Los Angeles, CA: Sage; 2007.
15. Holmes WR, Joseph J. Social participation and healthy ageing: a neglected, significant protective factor for chronic non communicable conditions. Global Health. 2011; 7(43):1–11. [PubMed: 21310041]
16. Madison, DS. Critical Ethnography: Method, Ethics, and Performance. 2. Los Angeles, CA: Sage; 2012.
17. Averill JB. Voices from the Gila: health care issues for rural elders in southwestern New Mexico. J Adv Nurs. 2002; 40(6):1–9.
18. Averill JB. Keys to the puzzle: recognizing strengths in a rural community. Public Health Nurs. 2003; 20(6):449–455. [PubMed: 14629676]
19. Winters, CA.; Sullivan, T. The chronic illness experience of isolated rural women: use of an online support group intervention. In: Winters, CA.; Lee, HJ., editors. Rural Nursing: Concepts, Theory, and Practice. New York, NY: Springer; 2010. p. 179-192.
20. Horton S, Johnson R. Improving access to health care for uninsured elderly patients. Public Health Nurs. 2010; 27(4):362–370. [PubMed: 20626837]
21. Weinert C, Cudney S, Kinion E. Development of *My Health Companion* to enhance self-care management of chronic health conditions in rural dwellers. Public Health Nurs. 2010; 27(3):263–269. [PubMed: 20525099]
22. Guo G, Phillips L. Key informants' perceptions of health care for elders at the US-Mexico border. Public Health Nurs. 2006; 23(3):224–233. [PubMed: 16684200]
23. Goins RT, Williams KA, Carter MW, Spencer M, Solovieva T. Perceived barriers to health care access among rural older adults: a qualitative study. J Rural Health. 2005; 21(3):206–213. [PubMed: 16092293]
24. Hawes C, Phillips CD, Holan S, Sherman M, Hutchison LL. Assisted living in rural America: results from a national survey. J Rural Health. 2005; 21(2):131–139. [PubMed: 15859050]
25. Torres, CC. Health of rural Latinos. In: Glasgow, N.; Morton, LW.; Johnson, NE., editors. Critical Issues in Rural Health. Ames, IA: Blackwell Publishing; 2004. p. 155-167.
26. Borders TF. Rural community-dwelling elders' reports of access to care: are there Hispanic versus non-Hispanic white disparities? J Rural Health. 2004; 20(3):210–220. [PubMed: 15298095]
27. Bales, RL.; Winters, CA.; Lee, HJ. Health needs and perceptions of rural persons. In: Winters, CA.; Lee, HJ., editors. Rural Nursing: Concepts, Theory, and Practice. New York, NY: Springer; 2010. p. 57-71.
28. Silverman, D. Doing Qualitative Research. 2. Los Angeles, CA: Sage; 2005.
29. Waves, Amber. [Accessed January 16, 2010.] Older women and poverty in rural America. http://www.ers.usda.gov/AmberWaves/September05/Findings/OlderWomen.htm. Published 2005
30. Habermas, J. The Philosophical Discourse of Modernity: Twelve Lectures. Lawrence, FG., translator. Cambridge, MA: The MIT Press; 1987.
31. Kincheloe, JL.; McLaren, P. Rethinking critical theory and qualitative research. In: Denzin, NK.; Lincoln, YS., editors. The Sage Handbook of Qualitative Research. 3. Thousand Oaks, CA: Sage; 2005. p. 303-342.

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32. Israel, BA.; Eng, E.; Schultz, AJ.; Parker, EA. Introduction to methods in community-based participatory research for health. In: Israel, BA.; Eng, E.; Schultz, AJ.; Parker, EA., editors. Methods in Community-Based Participatory Research for Health. San Francisco, CA: Jossey-Bass; 2005. p. 3-26.
33. Minkler, M.; Wallerstein, N. Introduction to CBPR: new issues and emphases. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health: From Process to Outcomes. 2. San Francisco, CA: Jossey-Bass; 2008. p. 5-23.
34. Denzin, NK.; Lincoln, YS. Introduction: critical methodologies and indigenous inquiry. In: Denzin, NK.; Lincoln, YS.; Smith, LT., editors. Handbook of Critical and Indigenous Methodologies. Los Angeles, CA: Sage; 2008. p. 1-20.
35. Agar M. An ethnography by any other name. Forum Qual Soc Res. 2006; 7(4):17–27.
36. Madison, DS. Critical Ethnography. Thousand Oaks, CA: Sage; 2005.
37. Averill JB. Merging critical ethnography with community-based action research in studies of rural elders. J Gerontol Nurs. 2005; 31(18):11–18. [PubMed: 16375093]
38. [Accessed March 15, 2012.] StateHealthFacts.org. http://www.statehealthfacts.org/profileglance.jsp?rgn#33#rgn#1. Published 2012
39. Averill JB. Getting started: initiating critical ethnography and community-based action research in a program of rural health studies. Int J Qual Methods. 2006; 5(2) http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4385.
40. Flick, U. An Introduction to Qualitative Research. 3. London, England: Sage; 2006.
41. Patton, MQ. Qualitative Research and Methods Evaluation. 3. Thousand Oaks, CA: Sage; 2002.
42. Fetterman, D. Ethnography Step by Step. 3. Los Angeles, CA: Sage; 2010.
43. Gough, B. Shifting researcher positions during a group interview study: a reflexive analysis and review. In: Finlay, L.; Gough, B., editors. Reflexivity: A Practical Guide for Researchers in Health and Social Sciences. Oxford, England: Blackwell; 2003. p. 146-160.
44. Sullivan, G. Art Practice as Research. 2. Los Angeles, CA: Sage; 2010.
45. Pink, S. Doing Visual Ethnography. 2. London: Sage; 2007.
46. Wagner, J. Observing culture and social life: documentary photography, fieldwork, and social research. In: Stanczak, GC., editor. Visual Research Methods: Image, Society, and Representation. Thousand Oaks, CA: Sage; 2007. p. 23-59.
47. Freire, P. Pedagogy of the Oppressed. New York, NY: Continuum Publishing; 1970.
48. Watson, J. Human Caring Science: A Theory of Nursing. 2. Sudbury, MA: Jones & Bartlett; 2012.
49. Wallerstein, N.; Duran, B. The theoretical, historical, and practice roots of CBPR. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health: From Process to Outcomes. 2. San Francisco, CA: Jossey-Bass; 2008. p. 25-46.
50. Lincoln, YS. Emerging criteria for quality in qualitative and interpretive research. In: Denzin, NK.; Lincoln, YS., editors. The Qualitative Inquiry Reader. Thousand Oaks, CA: Sage; 2002. p. 327-345.
51. Nightingale, F. Notes on Nursing: What It Is, and What It Is Not. Philadelphia, PA: JB Lippincott; 1992. commemorative
52. Springett, J.; Wallerstein, N. Issues in participatory evaluation. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health: From Process to Outcomes. 2. San Francisco, CA: Jossey-Bass; 2008. p. 199-220.
53. Byok IR, Corbeil YJ, Goodrich ME. Beyond polarization, public preferences suggest policy opportunities to address aging, dying, and family caregiving. Am J Hosp Palliat Med. 2009; 26:200–208.
54. Bradbury, H.; Reason, P. Issues and choice points for improving the quality of action research. In: Minkler, M.; Wallerstein, N., editors. Community-Based Participatory Research for Health. San Francisco, CA: Jossey-Bass; 2008. p. 225-242.
55. Johnson, G. Fire in the Mind: Science, Faith, and the Search for Order. New York: Vintage Books, a division of Random House; 1995.
56. Stein, DL.; Nadel, L., editors. Lectures in Complex Systems. Vol. 3. Redwood City, CA: Addison-Wesley; 1990. Santa Fe Institute Studies in the Sciences of Complexity, Lectures1991

NIH-PA Author Manuscript
NIH-PA Author Manuscript
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57. Binder JF, Roberts SGB, Sutcliffe AG. Closeness, loneliness, support: core ties and significant ties in personal communities. Soc Netw. 2012; 34(2):206–214.
58. Abbott S. Social capital and health: the problematic roles of social networks and social surveys. Health Sociol Rev. 2009; 18(3):297–306.
59. Polkinghorne, D. Practice and the Human Sciences: The Case for a Judgment-Based Practice of Care. Albany, NY: State University of New York Press; 2004.
60. Bourdieu, P.; Wacquant, LJD. An Invitation to Reflexive Sociology. Chicago, IL: University of Chicago Press; 1992.

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Table

Perspective on Social Networks: Foundations, Interpretation, Impact/Outcome

Sources	**Foundations**	**Interpretation/Process**	**Impact/Outcome**
Waldrop[6]; Kauffman[7]: Santa Fe Institute, complexity theorists	*People tend to organize according to needs, purpose*; collaboration/adaptation of networks occurs in cells, organisms, humans, communities, and systems	Observation, interviews, assessments, verification	*Understanding* these networks strengthens interventions in business, social health services, politics, funding
Wheatley[8–10]; Wiles et al[11]	*Community/network is the human web of connection*, perseverance, and resilience	Social discourse, re-engagement of people in their communities	*Resolution* of problems, social civil activism, and work for change
Greenhalg[12]; Kotelchuck et al[13]	*Core concepts*: interpersonal communication and influence; partnership	Use social activity surveys to map social networks	*Innovations, evidence, change*; meet community needs, improve social determinants of health, policy
Grbich[14]	Understanding *patterns of interaction* is key	Identify people, assess relational dynamics/power, produce a graphical analysis, confirm/adapt with data over time	*Insight* regarding key linkages, patterns, group behaviors over time
Holmes and Joseph[15]	*Social participation* improves older adults health, works as a protective factor	Provide network of services, opportunities for affiliation/dialogue	*Improvements* in morbidity/mortality, self-managed illness, symptoms
Madison[16]	*Performance* as social behavior gives insight to people's priorities, actions, motives	Analyze actions, communication patterns, scenes (contexts), agents (persons), agency (means, tools, instruments), and purpose (aim/objective)	*Accurate interpretation of human actions*, what they mean, and how we may support or help