SUFFERING IT OUT: MEETING THE NEEDS OF HEALTH CARE DELIVERY IN A RURAL AREA

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ABSTRACT

The health status of the people in the coal-producing counties of southwest Virginia is poor despite an apparent high provider to population threshold. This study used a qualitative approach to obtain information about accessibility to health care services and about perceptions of personal health status. Interview and focus group data revealed that the delivery of health care services is compromised by poverty and the large number of medically underinsured and uninsured individuals. Emergent themes included “suffering it out," a strong sense of community, quality time with provider and needed fixes. Another significant finding revealed the need for specialty providers. Community health nurses can provide a valuable service by making people aware of free and low cost prevention and prescription assistance programs, assist with understanding government health forms, and locating other low-cost health services for clients in their districts.

INTRODUCTION

Rural settings present an array of challenges for community health nurses including an ongoing struggle to offer the most optimal care with very limited resources. Prior studies have indicated a Rural Nurse Organization Digital Library relationship between the availability of primary health care providers and the health status of a population (Beaulieu & Webb, 2002; Pol, Rouse, Zyzanski, Rasmussen & Crabtree, 2001). It is generally accepted that when more primary care providers are available, a population will be healthier (McBride & Mueller, 2002). However there is a paradox in the coal-producing counties of southwest Virginia where the health status of the people is poor despite an apparent adequate supply of primary care providers (GMEC, 2000). Morbidity and mortality rates for heart disease, malignant neoplasms, chronic obstructive pulmonary disease and diabetes are high and people in this region tend to die at a younger age than the U.S. median life expectancy (East Tennessee State University, 1996; HRSA, 2000). Despite the data that describes the general health status of people and the provider-patient ratio in Southwest Virginia, little is known about how people here view their personal health status and what ideas and knowledge they have about the kind and quality of health care services that are available to them. Therefore, the purpose of this study was to explore perceptions of health and access to health care services in southwest Virginia. The research question that guided the project was, “If there is no acute shortage of primary care providers in southwest Virginia, what accounts for relatively poor health in the region?"

BACKGROUND

Southwest Virginia is in the geographical heart of central Appalachia and is a rural region defined by rugged ridges and remote valleys. Mountains extend from 4,000 feet in elevation on the loftiest peaks to 2,000 feet in the surrounding valleys. Although small towns dot the region, most of the population of almost 400,000 people is scattered among secluded communities in the hills and the natural narrow hollows of the area. Generally, people here are characterized as being hard-working and industrious. Although the region is transected by major four-lane highway systems, southwest Virginia does not lie on any of these direct transportation routes.

The coal-producing counties of southwest Virginia are considered economically depressed area since technological advances in the coal industry decreased the need for laborers. This area, like many other rural communities throughout America, must contend with the effects of corporate downsizing, business and industry closings and relocations, along with diminishing state funds and increased competition for the little government support that is available. Therefore, the challenge for community health nurses and other health providers in this area is to address the health care access and health disparities as described in Healthy People 2010 while controlling costs in a geographical area that continues to experience economic decline (U.S. Department of Health and Human Services, 2000).

Health Care in Rural Southwestern Virginia

Primary health care services are often seen as the basic foundation for health care and the entry point for specialized health care services. However, like many rural areas across the United States, residents of southwest Virginia do not experience the same level of access to basic primary and specialty health- care services that is available to urban Americans. This condition exists despite a Virginia survey that indicated an ample number of primary care physicians and nurse practitioners (Virginia Health Care Foundation, 2001). The reality is that access to basic health care services in southwest Virginia is complicated by poverty, inadequate transportation, geographical distances, the seclusion of small communities, an aging population and economic decline (AHCPR, 1996). The population includes disproportionately small numbers of younger adults and large numbers of elderly people. Low educational attainment and a high percentage of individuals on government assistance also contribute to low economic status and consequent poor health. A recent report by the Virginia Health Care Foundation (2001) indicated that southwest Virginia led the state in the percentage, 20.4%, of medically uninsured people and consequently, in the percentage of people not being seen by a primary care provider.

Educational attainment and personal income are key indicators used to predict the health status of a population (GMEC, 2000). In southwest Virginia, 47% of the population over the age of 25 does not have a high school diploma or a general education diploma. This high rate contrasts sharply with the Virginia State rate of 25%. In fact, 27%

of the people in southwest Virginia have less than nine years of formal education as compared with 11% for the rest of the state. Likewise, the poverty rate for southwest Virginia is twice the rate of Virginia as a whole, 20% compared to 10.5%, and per capita income in the southwest is 65% of per capita in Virginia. People with income levels at or below 200 percent of poverty are nearly twice as likely to be medically uninsured as people at higher income levels (Virginia Health Care Foundation, 2001). More than 25% of the population in southwest Virginia receives Social Security benefits but not all of these beneficiaries are elderly. Eight per cent of the region's population receives social security disability benefits. These beneficiaries represent those with poor health status and, given the small pension paid by social security, more than likely are poor or near poor.

In southwest Virginia, the ratio of the number of younger (18-45 years), working-age people to the number of older, non-working people is disproportionate, with the older non-working group outnumbering the younger, working group. Unemployed workers, part-time workers and homemakers comprise 75% of uninsured people in Virginia (Virginia Healthcare Foundation, 2001). Indeed, almost 77% of the uninsured are in the 18-64 age group and are those people who are unemployed or who work at part-time, low wage jobs. Out-migration of individuals and families in search of employment may account for the relative low numbers of working age people in the region.

Recruiting and retaining physicians and nurse practitioners in a region beset by economic decline remains a challenge. A lack of competitive salaries, shortages of specialty providers for consultation, the high cost of facilities and equipment, and social isolation are just a few of the obstacles to overcome when recruiting and retaining primary care providers. In addition, a shortage of nurses throughout the nation adds difficulty to the task of maintaining adequate nursing ratios. At present, local hospitals are experiencing a nursing vacancy rate of between 8 and 11%. Difficulties in recruiting providers to southwest Virginia has created a revolving door phenomenon of health professionals who come to the region for a short stay prior to leaving for more lucrative jobs in urban areas.

METHODS

This study used a qualitative approach to gather information from three informants and twenty-four participants in three focus groups. The intent was to elicit information that described their perceptions of the availability of health care services in southwest Virginia and how they viewed the relative health status of themselves, their family members and their neighbors.

Setting

The interviews and focus groups took place in a small rural community in Lee County, Virginia. Lee County is the Western-most county of Virginia and lies adjacent to Kentucky on the north and Tennessee on the south. The community [1], Spring Hollow, consists of approximately 80 families with about 325 people. This is a fairly typical southwest Virginia community where 40% of the people have less than a high school education and work in blue collar jobs such as with the state transportation department, in forestry, the garment industry, in the coal mines or nearby federal prisons. Some of the older male residents are retired or on disability from years of working in the coalmines. Many people work two or more part-time jobs and some work a full-time job along with a part-time job in order to provide for their families. Small towns a few miles away provide employment opportunities for some of the residents of Spring Hollow. There is a strong sense of community and family in Spring Hollow. In fact, most people identify themselves as first being members of the Spring Hollow Community and then of Lee County, Virginia. There are two churches in the community, Baptist and United Methodist. Cattle raising, tobacco growing and timer harvesting is done on a limited basis and often serves as a supplement to a full-time or part-time job.

Informants and focus group participants

Three informants were selected for individual interviews. Two elderly women, ages 63 and 62, were identified as potential informants by other members of the community because of their in-depth knowledge of the community and their ability to articulate the health care needs of its residents. These two women turned out to be key informants in that information derived from the focus groups and from conversations with other community residents could be verified or substantiated by them. The third informant, who was 34 years old, expressed interest in the study and asked to be able to participate. The informants were paid a nominal sum of money for their participation.

Participants for the three focus groups were recruited by word of mouth. One of the research team members announced the opportunity to participate in the study to the congregation in a local church. Two of the three focus groups were treated to dinner before the meeting and participants in all focus groups were paid a nominal sum of money. The third focus group was composed of individuals who wanted to participate but could not attend the “dinner” meetings. The groups consisted of 9, 10 and 5 participants. Two of the groups met in a local church hall where dinner was served and the third group met in one of the participant’s homes. Ages for participants in the focus groups ranged from the 20’s to the 70’s and there was a mixed representation of employment statuses that reflected the community’s demographics.

Consent

Institutional approval was obtained before the interviews were carried out. All of the informants and the focus group participants signed a human subjects’ disclaimer form and all had the study explained to them before the interviews and discussions began. The investigators made certain that everyone understood that they were under no obligation to participate in the study, that they could withdraw/leave the interview/focus group at any time and that all of the information gathered would be used in such a way that no one person would be identified. It was also explained that at any time during the discussion or interview that they could request that the tape recorder be turned off.

Prior to the data collection process, the investigators were concerned that the participants in the focus groups were well-known to each other and that some might be reticent to express their beliefs and views about health care in their community. As it turned out, the anticipated problem did not materialize. All of the participants engaged in active conversation and information sharing, agreeing or disagreeing with discussion points and with each other throughout the meeting.

Data Collection

All individual interviews and focus group sessions were tape recorded. Neither the informants nor the participants in the focus groups objected to having the discussions taped. The tapes were destroyed after transcription. There was only one instance where a participant asked for the tape recorder to be paused while a heated conversation about a local provider took place.

The investigators developed a series of open-ended, lead-in and discussion-generating questions to initiate a general conversation about health care and health care services. Examples of the questions used included: 1) “Would you describe some of the ways that you keep yourself and your family healthy?; 2) What do you do when you or someone in your family gets sick?; 3) What kinds of health-care services do you use most often?; 4) Have you had to change your doctor within the last 5 years?; 5) If you could change one thing about health care in your community what would it be?; and 6) What kinds of health services are not available to you?” As the intent of the questions was to stimulate conversation and to elicit those ideas and thoughts that were of primary concern to the participants, the researchers did not insist on asking all of the above mentioned questions. Two of the investigators served as “leaders” for the focus groups and guided the discussion to keep the discussions focused on issues of health, health care, and access to services in their community.

Data Analysis

The data were analyzed using strategies consistent with a qualitative approach. Each interview and focus group discussion was transcribed, organized, coded and interpreted in terms of recurrent verbal patterns and expressions. Each interview was transcribed, read and initially coded and interpreted before subsequent interviews with the idea that questions and discussion points could be generated for future interviews and discussions. Each of the investigators read and made comments on the transcribed interviews and then met to discuss interpretations. The dialogue that emerged between the investigators revealed congruent interpretations for most of the transcribed interviews.

Recurrent patterns of expression were grouped or synthesized into categories (decontextualized) that were then fit and linked together. The links were compared and contrasted and they in turn were linked back together into common themes. There was a constant looping backwards and forwards as new ideas and thoughts emerged and were identified from the data by the investigators. Four of the major themes that were identified included: 1) making do/making a shift and suffering it out, 2) sense of community, 3) quality time with provider and 4) needed fixes. In addition, for each theme identified, there seemed to be a general descriptor related in terms of “my story” that emerged. Each informant and focus group participant expressed the need to tell “their story” and the essence of these stories often served as narrative examples and descriptors of the themes. Excerpts from the stories are included with a description of the following themes.

Presentations of Themes and Interpretations

Making Do/Making a Shift/Suffering It Out. People seemed to have a sense that the way in which things occur to them and within the community was a way of life and that the best approach for them was to "make do," "suffer it out" or "make a shift." To the informants and focus group participants, making do, making a shift or suffering it out might involve a change in personal behavior, routine or method. It was not uncommon to hear the expressions, "this is just the way things are" and "we have to adjust." The investigators did not interpret this seemingly "fatalistic" approach to life as complacency, but rather a mechanism for adaptation and setting priorities in order to cope with life's everyday challenges and stresses. It was also a way that people could adjust their expectations to perceived reality and to life events as they occurred around them. There were some things that were seen by them as things that "could not be changed" or "challenged" by them as individuals or as a community. "Making a shift" or "making do" was perceived as a positive reaction to life events as compared to "doing without" which was perceived negatively. The health care that they received and basic health care services in their community were two such things that they perceived as things "they" couldn't change. Therefore, the informants and focus group participants stated that they "made shifts" to adapt to the existing system. For example, during one of the focus groups, a participant recounted:

> I used to go to the doctor on a regular basis but now I just have to shift away from that and go when I just get really sick…I don't take blood medicine no more because I don't have insurance to pay for it no more…just do and suffer it out…do without, I guess…

Or, as others related,

> You have to switch gears or make a shift from what you're used to doing, especially when you have kids. They need the care first and we as parents just make do without.
>
> When you get old, you just have to make do, do without and suffer it out. When I was working and had health insurance, I could go more often and it didn't seem to cost as much.

For many people in this study, putting food on the table and providing housing and clothing for their families came before their own health care needs. Although all expressed the importance of maintaining their health, it was seen as something intangible and difficult to obtain. Most made comments that "the system just didn't support working people." In fact, several focus group participants expressed frustration at the way that many people "fooled" the system into thinking they were "disabled so that they could get benefits" while "us honest and hard-working people just seem to get punished." Part of their frustration was based on the high cost of health insurance premiums and deductibles and the unwillingness of many of their employers to provide low-cost health care for their workers.

> I know I need to have more checkups, but I can't afford the premiums, so I just suffer it out.

When asked how they would compare their health and the health of their family members to the rest of Virginia, the informants and over half of the focus group participants identified either themselves or someone in their household as having a chronic illness. This finding supports research from other rural areas that indicates people in rural areas are at a greater risk for such diseases as cancer, heart disease and diabetes and have a greater difficulty seeking out preventive care (Krummel, Humphries & Tessaro, 2002; MMWR, 2002; Rosswurm, 2001).

Interestingly, the informants and participants in this study related the "poor economy" of the region with the "poor health of the people." When asked to explain this relationship, most people explained that "when you live in a poor area," it was expected that the health of the people here would be also poor. Further exploration of this idea resulted in a discussion of "how it has just always been this way." Most people do not see a change in this status unless another large industry comes to the area to provide jobs like coal mining once did. Historically, when coal mining became unionized, health care was part of the labor agreement.

Sense of Community. Strong ties to the community and to people living in that community emerged as an important theme. Just about everyone had family within close geographical proximity to Spring Hollow and southwest Virginia, eastern Kentucky or northeastern Tennessee. Several remarked that even though they may have left the area for "a time" to attend school or for military service, but that they missed the "hills and hollows" enough to return and raise their families. This heritage can be traced through common surnames throughout the area and it is "local knowledge" that you need to be "careful who you talk about as everyone is related" in some way or another. Many of the family names and actual family members can be traced one hundred or more years to the region. People express a strong allegiance and pride in belonging to the region and they regard their neighbors as "family" even if a blood relationship does not exist. In addition, membership in the local churches served to cement community relationships and people watch out for and also support their neighbors as members of their church.

The sense of community and neighboring extends to concerns for the health and well being of the residents. During the context of the interviews and the focus groups, it was not unusual for a person to relate a tale of woe only to add that someone else in their community, a neighbor or someone just "down the road" was "worse off." For example:

> I am lucky – I have pretty good health, good insurance and good doctors. There are so many of my neighbors who do not have this. In this country of ours, there is no excuse that all can't have health care plus their medications. This is a big problem and our congressmen need to act fast.
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> I am able to get to see my doctor when I need to but so's many's can't and it is just sad. My neighbor lady can't get her medicine when she needs it and just can't wade through all the paperwork that is needed. I tried to help her read it, but I don't understand much of it neither. She has no one

> to drive her to the insurance office and my son comes by and takes her when he can. There seem to be so many like her. It is just sad.

The strong sense of community, however, can have adverse implications for health care providers who are not from the region. These providers are often viewed as “outsiders” who come for a short period of time to take “from” the community but not participate in community activities or give back to it. For example, many physicians and nurses who come from the “outside” provide home schooling for their children or send them away to boarding schools. The informants were quick to point out, however, that there were many health care providers who came to the region as outsiders but who did make an attempt to become part of the community. These particular providers were held in high esteem.

It has been written (Batteau, 1990; Best, 1996) that the people of Appalachia are often slow to warm up to and they hesitate to develop trusting relationships with people who are not from or who were not born in the area. The reluctance is reflected in historical accounts of “outsiders” who exploited Appalachia not only for its natural resources but for its rich cultural heritage, yet portray its inhabitants with unflattering terms. As one residents of Appalachia explains:

> Outsiders “didn’t trust us hill folk to speak plan or act for ourselves….they became our planners and our actors. And so they’ll go again, leaving us and our poverty behind” (West, 2003).

Mr. West goes on to proclaim that many outsiders make claims of wanting to save Appalachia and the Appalachian people but, in actuality, they come to take away from the area and impose a way of life that is not compatible with the lifestyles of the people living there.

Quality Time with Provider. Another important theme that emerged and was seen as an integral part of the overall health status of the people here was an individual’s relationship with their primary care provider. This was especially important for the older informants and participants and for those with chronic illnesses. Quality time with a provider, whom they identified as physicians and nurse practitioners, may reflect back on the strong sense of community and the desire for providers to become part of that community. “Quality time” was viewed as the mutual giving of respect and knowledge-sharing that occurred between the informant/participant and the provider. The informants were quick to identify and list the names of the providers in their community who seemed to respect them as individuals, who listened carefully to their complaints and symptoms and acknowledged the fact that the informants “knew their bodies best.” For the informants and the focus group participants, the time spent with health care providers was very important, whether it was five or fifty minutes. They acknowledged the fact that they lived in an area far away from basic services and that their physicians and nurse practitioners were making sacrifices to practice here. For this reason, many stated that they didn’t mind waiting for a provider an hour or more after the scheduled time if the provider acknowledged the wait and apologized.

However, during the course of the focus groups, it was discovered that it was very common for people to wait upwards of four or more hours to see the provider even if they had a scheduled appointment. Rarely did they receive an apology from the staff or the provider.

Almost all of the informants identified that providers in their area “seemed” to be overworked and that many providers “overbook” the daily caseloads with the result that the provider sees them as a number and not as a person. Others defended the providers by stating that most of the providers “overbook” because there were so many people who didn’t show up for scheduled appointments and, in addition, that there were so few providers that they felt obligated to see everyone who called. One point of interest that was revealed was that, for most, “waiting” seemed to be an accepted part of the health care experience. Several informants stated that they had to take off a day from work to go to the doctor or take a relative because they knew that it would take “all day.” Even more interesting was that the “waiting” did not affect their responses and discussion of “quality time with provider.”

Needed Fixes. One important theme that emerged from this study was that people wanted to help each other and in doing so wanted the investigators to understand what could make the “health care system better.” All of the informants and focus group participants indicated a need for a better health care system in the United States. They were distressed that there seemed to be a wide discrepancy between those who were able to afford health care and those who were not. One informant stated that “we need to have a way that all people can be taken care of and get to see a doctor when they need to.”

Most of the informants in this study were associated with health care plans that required so large a deductible that it was impossible to cover all the family members. In these cases, the individuals enrolled their children in a state-supported system and did without their own health care insurance. Others indicated that they used the local emergency room for their “real illness” experiences and still others noted that they generally “did without.” Of concern to the investigators was that delays in seeking out health care could exacerbate many chronic illnesses and could also thwart any primary prevention strategies. Even if the informants and participants stated that they had health insurance coverage or Medicare or Medicaid, 80% of them had no vision or dental coverage.

Another needed fix was “easy forms.” The elderly informants and focus group participants stated that their Medicare claims were confusing to process and interpret and that the premiums still cost so much that they couldn’t afford their medications or even routine health care visits on their limited, retirement incomes. Just about all indicated a frustration with having coverage for prescriptive medications. They recognized that this problem was more than a local problem and that many people throughout the nation were in similar situations.

Another “fix” was the need for more qualified health care specialists for their area and especially those that could provide for eye diseases and for the more chronic conditions such as respiratory diseases and cancer. Several of the focus group participants asked, “Why can’t our government do something to help all people?”

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[1] Fictitious name of the research community

SUMMARY AND IMPLICATIONS FOR FUTURE RESEARCH

People in southwest Virginia recognize that they are not as healthy as the rest of the state and that they live in an economically poor region where it is harder to attract and keep health care providers. In interpreting the results of the study, it would appear that the major factors that contribute to this poor health include: 1) a large number of medically underinsured and uninsured individuals; 2) a shortage of specialty health care providers and 3) knowledge of available prevention services. Consultation services are available to providers in southwest Virginia with specialists in larger medical complexes though TeleMed. Physicians and nurse practitioners do make use of this service, but they indicated that in many instances the ill person needs to be seen by a specialist. Even if the cost of the specialist is covered by insurance, transportation to the specialist may be 200 or more miles away and, therefore, involves an overnight stay. This is problematic for those on very limited budgets and for family members who must take off work to transport their ill relative. Several of the providers that the investigators spoke with indicated that many of their referrals are ignored by their patients for this reason.

The results of the study also indicated that community health nursing can and does play an important role in the health care of people in this region. A few suggestions for improved care would include:

- A focused effort to deliver health promotion and disease prevention information to residents of the area including a listing resources for low cost services such as mammography, diabetes testing, colonoscopy, etc. Many of the informants and participants in this study were unaware of the services available to them.
- Identification of those dentists in the area who will provide low-cost or free dental care. Free dental services are offered once a year at a Remote Area Medical Expedition (RAM) event in Wise County. However, a mechanism still needs to be developed whereby ongoing, low-cost or free dental services can be obtained by those in need.
- Identification of “prescription aid” programs and pharmacies that offer assistance to those who need help paying for their prescriptive medications. Many of the people in this study were unaware that prescription services were available.
- Identification of individuals, including volunteers, in the community who help with Medicare and Medicaid paperwork.
- Greater partnership relations between providers and the community organizations and populations.
- Although many of the community churches in the community are small, there may be a way in which they could band together to support a faith-based initiative such as Parrish Nursing for the community. One faith-based hospital exists in the area and the nuns are very active in their attempts to help with the delivery of services. In fact, one of the sisters operates a mobile health van in the more remote areas and she was the principle organizer for the RAM event.
- The community, the local university, the health department, local health practitioners and individual citizens recognize the need for low cost services

> in the area and have worked together to sponsor a RAM event each year in Wise county. Perhaps this same group could work to increase political awareness for the need for low cost-health services to this area.

As a result of this study, the investigators would like to explore in greater detail the social and cultural dimensions of health in rural and medically underserved areas. For example, on what basis do people prioritize their health care needs and how do they go about making decisions with respect to health care? It is anticipated that this study can and did lay the groundwork for research that will investigate these questions along with other dimensions involved in perceptions of health and illness.

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