PROJECT GENESIS: COMMUNITY ASSESSMENT OF A RURAL SOUTHEASTERN ARIZONA BORDER COMMUNITY

by

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As members of the Scholarly Inquiry Project Committee, we certify that we have read the scholarly inquiry project prepared by Amanda Dawn Bennett entitled Project GENESIS: Community Assessment of a Rural Southeastern Arizona Border Community and recommend that it be accepted as fulfilling the scholarly inquiry project requirement for the Degree of Doctor of Nursing Practice

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This scholarly inquiry project has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

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"It takes a village to raise a child" is an often quoted African proverb. In conducting this research, the proverb has been affirmed. It takes a village to raise healthy and happy children to be responsible and healthy adults able to nurture future generations. I wish to thank the villages, or communities, of Willcox, Arizona and surrounding communities for not only aiding in my "raising" but also allowing me to come back to my home town and conduct this research. Context is everything, and it "takes a village" to successfully complete the requirements for the degree of Doctor of Nursing Practice. I need to acknowledge my village. Everyone who has touched my life over the past 30 years has in some way contributed to my context, and subsequently, this work. I want to thank the participants who gave so selflessly with rich and open responses during interviews and focus group sessions. Your names and stories will remain confidential, but the marks you left on my heart cannot be erased or replaced with pseudonyms.

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Most of all, thanks be to God, who makes all things possible. May I use Your gifts responsibly to bring You glory and honor.

Amanda

DEDICATION

This dissertation is dedicated to all those living in rural communities across our country. I hope that this research adds to your voice. May you be blessed with safe, high quality, and culturally competent healthcare, at home.

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ABSTRACT

Purpose/Aims: The aim of this study was to understand the health issues of a rural Southeastern Arizona border community. More specifically, this study used community assessment with ethnographic principles to: 1) Conduct a community assessment centered on definitions of health, access to care, quality of care, and health needs in a rural Southeastern Arizona border community; and 2) Compared the findings of this study to previous studies, models, and theories of rural nursing and rural health.

Background: It is important to understand that each community has a unique set of health priorities that are dictated by these factors; making every rural community different. Much of the work that has been done in rural America has been performed in the Midwest, Southeast, or Northern states. There is limited information regarding Arizona or even Southern US border communities and whether previous work can be generalized to areas that have not been studied.

Sample and Methodology: This study utilized community assessment with ethnographic underpinnings through the use of focus groups, key informant interviews, participant observation, and secondary data analysis of existing community data. Sampling for the focus groups and key informants was purposive. Focus groups included: 1) participants who use local health services and 2) participants who do not.

Analysis: Lincoln and Guba's (1985) guidelines for rigor in qualitative studies was utilized. Thematic analysis and thick description were used to analyze data. Theoretical triangulation was performed between individual, group, and community level data with theoretical linkages made to community capacity theory and rural nursing key concepts.

Implications and Conclusions: The location of this project, rural Arizona community, near the US-Mexico border, posed an interesting contrast to the proposed concepts widely being used today. From this study, healthcare leaders in this community are better equipped to provide relevant, high-quality, and safe services; but an informed community emerged that has an interest in promoting the health and well-being of the community as a whole.

CHAPTER ONE

THE PROBLEM

Sixty million people in the United States (US) are classified as living in "rural" areas and 55 million are living in "non-metropolitan" counties (US Bureau of the Census, 2002). This accounts for approximately 20% of the US population living in rural America (Institute of Medicine [IOM], 2004). It is imperative for nurses in rural communities to understand the nature of rural environments to be more effective health care providers. This paper will seek to discuss the importance of rural healthcare providers knowing their community for the basis of providing high quality, safe, and culturally competent care. This chapter will seek to outline rural health care delivery in regards to 1) defining rurality and what is meant by "border", since there are differing opinions throughout the literature and this definition affects governmental health care funding and services provided to populations; 2) characteristics of the rural population, to better understand the culture in regards to age, ethnicity, socioeconomic status, and views of health; 3) specific characteristics of rural health delivery systems in regards to care continuums; 4) health care disparities that subsist in these exigent environments to better understand the challenges presented to health care providers.

Purpose

The purpose of this study was to establish the need for rural nurses to be proactive in knowing their community, to ensure the provision of culturally competent and valuable health services, while empowering the community to increase awareness of the community's health issues. Beginning rural nursing concepts, as proposed by Lee 1998;

Lee and Winters (2006) and Bushy (2000), attempts to provide this knowledge to nurses through outlining key concepts; however, it is uncertain whether these key concepts hold true for all rural communities, primarily a rural Southeastern Arizona border community.

Specific Aims

This study encompassed the use of community assessment with ethnographic principles to identify the contextual factors of health in a rural community. This study will focus on English speaking members of the community. To accomplish this overall goal, the following aims were addressed for a specific rural community: definition of health, access to care, perceptions of care, and community health needs and issues.

Background and Significance

Any community, whether rural or urban, has different health priorities that are related to differences in demographics, health behavior, geographic isolation, and access to health care. Geographic location and isolation has been established throughout the literature and the impact they have on health. It is important to understand the demographics of the rural milieu, meaning the age and ethnicity of rural residents and the socioeconomic climate. Of equal importance is the rural dwellers definition of health and healthy behaviors that are practiced within rural communities. All of these characteristics of rural populations are shaped by the populations' access to health care.

Age

The age configuration of rural populations tends to get older as urbanization decreases (Centers for Disease Control and Prevention [CDC], 2002). In 2006, the US had 36 million elderly persons, considered age 65 and older. This number is an increase

of 3.7 percent since 2000. Metropolitan regions gained 4.1 percent more elderly between 2000 and 2004. Whereas, non-metropolitan areas only saw a 2.3 percent increase. Despite this lower population growth, non-metropolitan areas generally have a higher proportion of elderly when compared to metropolitan areas, constituting almost 15 percent of the rural population compared to 11.7 percent in urban areas (Economic Research Service [ERS], 2007).

The nation's elderly population is expected to double by 2050. The concentration of rural elderly is projected to increase, especially into 2011 when the first members of the baby-boom generation will be reaching age 65 (Rogers, Goldstein, & Cooley, 1993). Woods and Poole (1997), later projected, that by 2020, the non-metropolitan population would be highest in the 55 – 69 age groups. Couple these projections with an in-migration of retirees into rural communities and an out-migration of younger people, in order to find employment, and the end result is an aging rural population (ERS, 2002). In considering the high concentrations of elderly in rural areas, a challenge is presented to rural communities since the demand for social and health services increases as the population ages, when rural communities are already challenged to access baseline services.

Ethnicity

In the past, rural dwellers tended to be white and native born residents (US Congress, 1990). However, the racial and ethnic makeup of rural communities is dramatically changing. Minorities now comprise 18.3 percent of non-metropolitan population nationwide and are geographically dispersed throughout the nation (ERS,

2007). The number of Hispanics grew substantially between 1990 and 2000, by 70 percent. This is a higher percentage than any other racial or ethnic group (ERS, 2003). Contrary to popular belief, this growth is not just in the southwest, due to its close proximity to the Mexico border; in fact, approximately half of the rural Hispanic population lives outside of the traditional southwestern US (Whitener & McGranahan, 2003).

The Asian/Pacific Islander group has also been growing in rural communities. About one percent of all non-metropolitan residents in the US (533,108 persons) are Asian / Pacific Islanders. However, this group is not geographically concentrated as are other minorities, for example, African Americans in the south, Hispanics in southwestern States, and Native Americans in the western States. Of all Asian / Pacific Islanders living in non-metropolitan counties, 53.4% live in the non-metropolitan counties of the seven states of Hawaii, California, New York, Texas, Georgia, Washington, and Oregon. Of these states, only three rural counties, all in Hawaii, have the majority of the population Asian / Pacific Islander (Probst, Samuels, Jespersen, Willert, Swann, & McDuffie, 2002).

Socioeconomic

Throughout the mid-20th century, farming dominated rural economies. In today's global economy, that is not the case; seven out of eight rural counties are dominated by manufacturing, services, and other employment opportunities, not related to farming. Job growth in rural farming communities is now from agribusiness, processing and marketing of agricultural goods.

Rural economies now depend heavily on three main assets to generate their economies: natural amenities for tourism and retirement; low-cost, high quality labor and land for manufacturing; and natural resources for farming, forestry, and mining (Whitener & McGranahan, 2003). This has led to a diversification of rural economies nationwide. Those rural areas, that sustain their economies with the natural amenities, attracting tourism and retirees, have benefited from growth. This has been accomplished through the immigration of retirees that help in boosting the tax base that helps sustain local businesses. However, those rural communities that rely on their natural resources for farming and mining have had declining economies due to an out-migration of younger working-age people, resulting in lower tax bases and dwindling populations (ERS, 2002). Despite the growth found in rural communities that sustain their economies through the in-migration of retirees, there is a resultant socioeconomic strain placed on these communities to provide health services for this aging population. As mentioned earlier, the demand for social and health services increases as populations' age. This places further burden on rural communities that are already challenged to provide and access baseline services.

Despite the rural assets, rural communities continue to struggle do to a lack of well-educated and skilled workers. In 2000, only 17 percent of rural adults over 25 years of age had completed college, which is half of the percentage of their urban counterparts. In today's economy, manufacturing employers are interested in rural areas that include well-educated and skills workers that accept lower wages. In 1999, approximately 27 percent of rural workers, mostly women and minorities, held low-wage jobs (ERS, 2000).

Rural areas that have poor public school funding, lack of post-high school education, lacking educational attainment, and high economic distress are having difficulty attracting businesses into their areas (Whitener & McGranahan, 2003).

Poor rural workers often work part-time, live in female-headed households, and seldom have more than a high school diploma. These workers seldom receive health insurance through their employers and rely more heavily on state Medicaid programs. Rural working families also rely more heavily on benefits from assistance programs and less on family income earnings than working non-poor families (ERS, 2000). Generally, rural residents are less likely than urban residents to be insured for their health care costs, particularly by private insurance. Since rural communities are primarily comprised of small business owners, ranchers, and farmers, it is difficult for them to provide healthcare coverage for all their employees. Hence, it has been demonstrated that living in a rural region has a strong and rather unfailing negative effect on the rural dwellers economic chances (Ricketts, 2002).

As discussed previously, the ethnic makeup of rural populations used to be primarily white, but is now changing dramatically to include all ethnic groups. It is important for rural health care workers to understand the demographics, related to ethnicity and socioeconomics, within their communities, since it has been shown that poverty is a more prevalent problem for minority groups. Since minorities are not only more likely to be poor, they are also more likely to live in communities that have tighter constraints on total economic resources. Counties with high concentrations of minorities typically have income and assets that are two-thirds of the national average. This suggests

how difficult it is for rural communities to improve their economic status and that it is nearly impossible for individual residents to improve their own status without leaving their communities (Samuels, Probst, & Glover, 2003).

Definition of Health

Rural residents are 20 percent more likely, than urban dwellers, to consider themselves in fair or poor health (Ricketts, Johnson-Webb, & Randolph, 1999). In 2001, 40 percent of non-metropolitan elders age 60-64 considered themselves in excellent or very good health. By age 85 this number declined by almost half, only 21 percent considered themselves in excellent or very good health (ERS, 2002). Nearly 37 percent of non-metro elders reported their health as fair or poor, compared with 32 percent of metro elders. Self-assessed health is a critical measure because it is associated with mortality, quality of life, and other important indicators of health status such as physical exams (Rogers, 2002).

Rural dwellers are less likely to participate in preventative behaviors, such as seat belts use and exercise, or have preventative medical screenings done. This may be attributed to a lack of access to care. It has been cited that residential location has an effect on health status indirectly. Non-metro elders are more likely to have characteristics associated with poorer health because they tend to be less educated and financially worse off than the metro elderly, and lower socioeconomic status is strongly associated with poor health. Non-metro elders are also more likely to have chronic conditions that darken self-assessed health status and impair functional ability (Rogers, 2002).

Infant mortality in rural regions is slightly higher. This is significant since infant mortality is a worldwide indicator of health. Also of special note are death rates resulting from accidents are 40 percent higher in rural areas (Ricketts, Johnson-Webb, & Randolph, 1999). This substantial difference may be attributed to rural residents being less likely to where safety belts and the majority of the workforce being manual laborers, the potential for job-related injuries is higher.

Rural dwellers tend to have higher rates of chronic disease and this is presenting itself as a significant problem in rural America. The majority of chronic diseases seen in rural areas include: heart disease, hypertension, diabetes, arthritis, and certain vision and hearing impairments (Ricketts, Johnson-Webb, & Randolph, 1999). The increased incidence of chronic disease in rural regions is attributable to rural residents' propensity to smoke, drink alcohol, be obese, and a lack of physical activity (CDC, 2002).

Definitions

Two definitions are central to any discussion on health in rural environments: "rural" and "border". The degree of each of these factors has an immense impact on all facets of healthcare through creating various barriers to care, culture, values, beliefs, and the health needs of the community.

Definition of Rural

It is imperative to have a working definition of rural when describing the rural milieu since the characteristics that distinguish rural places from urban communities have important effects on health service delivery. These definitions were designed and are utilized for statistical purposes targeting programs and funding needs. Unfortunately,

there is not a gold standard definition of rural. However, there are two primary definitions of "rural" utilized at the national level for health care policy: the Office of Management and Budget (OMB) metropolitan/non-metropolitan classification of counties and the United States (US) Bureau of the Census classification of areas and population. Maria Hewitt, a prolific author of several governmental texts regarding the definition of rural, states it best, "the perceived magnitude of rural health care problems and the impact of any change in public policy depend on how 'rural' is defined" (1989).

United States Bureau of the Census Classification

The US Census Bureau bases its definition of rural on a combination of population density, relationship to cities, and population size. To understand this definition of rural, one must first understand the definition of urban. The Census Bureau (2002) defines "urban" as "comprising all territory, population, and housing units in urbanized areas and in places of 2,500 or more persons outside urbanized areas" (US Census Bureau, 1995, p. 1). An "urbanized area" (UA) is defined as a "continuously built-up area with a population of 50,000 or more" (p. 2). A UA includes "one or more central places and the adjacent densely settled surrounding area, with a population density exceeding 1,000 inhabitants per square mile" (p. 2). "Rural" is then defined as "any territory, population, and housing units not classified as urban" (p. 1). Hence, a rural place is any incorporated place or census designated place with fewer than 2,500 inhabitants that is located outside of an urban area. Therefore, rural communities can have population densities as high as 999 per square mile and as low as 1 or 2 per square mile.

Office of Management and Budget Classification

Historically, the OMB classified counties on the basis of their population size and incorporation with large cities. This agency differentiated between metropolitan and non-metropolitan areas based on Metropolitan Areas (MA). Over the past decade several governmental and non-governmental agencies urged the OMB to no longer base rural classifications from MAs but to better differentiate all areas on entire land surface areas. In response to this resounding request, OMB created micropolitan areas using the same criteria as those used for MAs (ERS, 2006). Current OMB standards state that each MA must include at least: "one city with 50,000 or more residents, or a Census Bureau-defined urbanized area (of at least 50,000 residents) and a total metropolitan population of at least 100,000" (Ricketts, Johnson-Webb, & Taylor, p. 5, 1998). These standards also outline that the county that contains the largest city becomes the central county of a MA. Any adjacent counties that have at least fifty percent of their population in the urbanized area surrounding the largest city are also included in the MA. Additional "outlying counties" are included in the MA if a considerable percentage of the employed people in the county commute to the central city.

As previously mentioned the OMB defined those areas that were not a MA to be considered nonmetropolitan and are therefore, rural. However, with the advent of the micropolitan area – this definition has changed considerably. Any nonmetropolitan county with an urban cluster of at least 10,000 persons or more becomes the central county of a micro area. As with MAs, outlying counties are included if commuting to the

central county is 25 percent or higher, or if 25 percent of the employment in the outlying county is made up of commuter from the central county (ERS, 2006).

Classification Comparison

It is important to keep in mind that neither the OMB's or the Census Bureau's definition of rural does not completely and adequately capture the true essence of rurality nor provide a universal system that accurately distinguishes urban from rural populations or places. A shortfall of these two definitions is they each offer two dichotomous categories in which to classify people. Both classifications fail to adequately capture the "variability inherent in the urban/rural continuum" (Weinert & Boik, p. 454, 1995). It is clear after examining these two methods of defining rural, conclusions about health will be drastically different when these two classifications are utilized in comparing two different populations. Hewitt (1989) cites "rural areas are not defined uniformly for purposes of federal program administration or distribution of funds" (p. 41). This can further undermine efforts to methodically assess rural health and delivery systems among rural dwellers, which creates larger health care problems, related to policy and funding, for an already disparaged population.

The Census Bureau has attempted to remedy this problem by adding an additional delineation to its definition, "frontier". Frontier areas are defined as "rural areas with six or fewer persons per square mile" (US Census Bureau, 1995). This delineation is useful in that it further clarifies the rural continuum but it fails to offer any insight to the urban/rural continuum. The OMB has also attempted to remedy this problem through the development of mircopolitan areas which subdivides previously undifferentiated

nonmetropolitan areas into two distinct types of counties – micropolitan and noncore, in hopes of better targeting rural-based programs (ERS, 2003).

Definition of "Border"

For the purposes of this paper, the southern US-Mexico border is of interest. This includes Texas, New Mexico, Arizona, and California. The US Department of Health and Human Services (HRSA) is the foremost authority on defining "border" due to their interest in improving access to health care services for people who are uninsured, isolated or medically vulnerable. Border regions were defined by different entities using criteria of proximity to the border. One definition identifies only those counties adjacent to the U.S.-Mexico Border as "Border Counties" (HRSA, 2004). The U.S.-Mexico Border Health Commission (USMBHC) (HRSA, 2004)) expands that definition to include all counties within 62 miles of the Border. The Texas Controller of Public Accounts broadens the criteria by adding counties considered as directly affected by the economic impact of border commerce thus extending the area to approximately 100 miles from the border in Texas (HRSA, 2004). Other definitions include larger areas. In Arizona, totals for the following geographic areas are included: within 62 miles of the border and more than 62 miles from the Border. HRSA (2004) defines "border" as follows: within 62 miles of the border, 62-300 miles from the Border, and more than 300 miles from the Border.

A unique characteristic of the US-Mexico border region is the magnitude and diversity of the human capital residing within its boundaries. On the US side, the four border States (California, Arizona, New Mexico, and Texas) were home to 65 million

people in 2003, over one-fifth (22.4 percent) of the population of the country. About 6.9 million of them lived in the area extending 62 miles inland from Mexico. The Mexican side had a similar high concentration of people, with the larger border cities hosting most of the population (HRSA, 2004).

Significance to Nursing: Quality of Healthcare and Rural Communities

The cornerstone of an effective provider of care is ensuring culturally relevant, high quality, and safe care is provided – regardless of where care is obtained. Compromised quality is characterized by inappropriate overuse and underuse of health services with the resultant detrimental human and financial costs to society (Burstin & Wakefield, 2004). Quality and safety initiatives have evolved significantly since introduction into the mainstream healthcare literature through the IOM's report "To Err is Human: Building a Safer Health System" (2000). Highlights of this report revealed that between 44,000 and 98,000 people die as a result of medical errors annually. These deaths in addition to medical errors carry an annual economic burden of $17 to $29 billion. This manuscript was followed by another IOM report "Crossing the Quality Chasm" (2001) that further identified the need to overhaul the present healthcare system; identifying fundamental changes to aid in closing the quality gap and save lives. It also asserts the healthcare environment should be safe for all patients, in all of its processes, all of the time – regardless of geographic location.

Although these reports do a wonderful job of delineating the strategic goals and actions to be carried out to improve healthcare in America, they lack a rural focus. After publication of these reports, there was a great deal of interest in improving the quality of

rural healthcare; however many initiatives never filtered down to the rural healthcare providers due to a lack of transferability, applicability, and relevance (Moscovice & Rosenblatt, 2000). A conceptual framework was needed for health care quality in rural environments that included acknowledgement of individual environments and characteristics to aid in articulation and implementation at the local level (Calico, Dillard, Moscovice, & Wakefield, 2003). In 2004, this issue was remedied with IOM's release of "Quality Through Collaboration: The Future of Rural Health". This report has bridged the gap between urban and rural quality initiatives; providing strategies to address the challenges in rural communities. These challenges include the overall heterogeneity of rural communities in regards to culture, size (both population and land mass), remoteness from urban areas, and economic and social characteristics.

The IOM (2004) generalizes: the smaller, poorer, and more isolated a rural community is, the more difficult it is to ensure availability of high-quality health services. This is primarily due to the limited care continuum available in rural environments, with fewer health care organizations and professionals of all types, less choice and competition among the entities that exist, and broad variation in their availability locally. Added to these limitations is an aging population that exhibits poor health behaviors (i.e. when compared to urban – higher smoking and obesity rates; lower exercise rates) and require more chronic health maintenance which places an enormous disease burden on local resources (Ricketts, Johnson-Webb, & Randolph, 1999). For this reason the primary impetus of federal agencies, thus policy, is to aid rural communities in quality initiatives is to aid in the elimination of health care disparities (Calico et al., 2003).

Objectives

The objectives of this study are two-fold:

1. To conduct a community assessment on using ethnographic principles to evaluate English speaking members of a rural Southeastern Arizona border community to inform and empower local nurses, healthcare institutions, and community to discover, understand, and act on the entire community's health issues.
2. To compare the findings of this study to previous studies, models, and theories of rural nursing and rural health.

Assumptions: Characteristics of the Rural Health Delivery Systems

Numerous characteristics of the rural health care environment directly impact the measurement and improvement of quality. These include: 1) low population density with increased travel times to health care, 2) health care facilities with low volume fixed overhead, 3) financial fragility, 4) health care provider shortages and lack of professional staffing, 5) inadequate reimbursement and investment, 6) lack of visionary leadership and staff training 7) inadequate information technology, 8) more complex decision-making requirements, and 9) a scarceness of resources in general (Calico et al., 2003; Wakefield, 2001).

Although rural residents comprise about one-fourth of the US population, they do not have the same access to care as their urban counterparts. Health care delivery in rural areas is problematical due to poverty, inadequate transportation, large geographical distances, an aging population base, and rural economic decline (Schur & Franco, 1999). There is a substantial need to improve access to health care in rural regions while at the

same time control health care costs. Delivery of rural health services is challenging since not only are providers dispersed over a large geographical space, the population density for which they provide care can be significant.

Care Continuum

Rural continuums of care are exceedingly diverse depending on the population of the non-metropolitan area, economic climate, and proximity to urban delivery systems. Often times the rural dwellers continuum of care must include traveling outside of the rural environment into a metropolitan area. This is usually the case when a patient requires specialty care. Other rural continuums have specialists and ancillary health services that travel from urban settings to provide care in the rural milieu several times every month to facilitate access to care. The broader continuum of care in a rural region results in improved health status and outcomes. As the continuum of care is narrowed, health status and outcomes decline (Ricketts & Heaphy; Schur & Franco, 1999).

Quality and Healthcare Disparities

Rural healthcare quality is vital, yet challenging, to every rural community, mainly due to the presence of disparities. These disparities present immense challenges to rural healthcare systems and providers; compounding the struggle to provide relevant and high quality health services to rural communities. The IOM has published "Guidance for the National Healthcare Disparities Report" (Ricketts, 2002) in which geography is described as a determinant in health care disparities related to access to care, quality, and service utilization. This report was compiled by the Agency for Healthcare Research and

Quality (AHRQ) with the goal of presenting it to Congress to identify the extent of disparities in the US and focus on the areas needing the most assistance.

Disparities within rural healthcare are multifactorial. They include: 1) geographical distance, 2) cultural values, and 3) socioeconomic factors. The lack of easy geographical access to essential services is one of the primary concerns in the provisions of health services. The exacerbating factors related to geographical disparities include unpaved roads, long distances to travel for care, and a lack of public transportation. Distance to health care is one of the most integral geographic features that may affect health status and health outcomes – contributing to disparities. Although geographical location is associated with wide variations in access to care, health care utilization, and health status, two elements of geography are not well understood and warrant further study – distance, in regards to time and topography, and weather (Ricketts, 2002). Further research needs to be done to examine the relationship between distance of care and health status or outcome.

Cultural values of rural residents can further restrict their access to care. If health services are not considered culturally sensitive, they will not be utilized by the population for which they exist. Literacy and language barriers exist due to limited education levels and the increasing minority, specifically Hispanic, population in rural sites (ERS, 2003). Traditional beliefs may further prevent health care utilization if culturally sensitive techniques are not utilized by healthcare providers. For example, patients tend to have their own traditional practices they use to maintain their own health status. If these patients are not encouraged to use these practices by their provider (as long as they are

not harmful) they may self-restrict their utilization of that provider. Another cultural technique that may come under the scrutiny of culturally insensitive providers is the use of traditional healers. This practice is usually seen in densely populated Native American areas which are generally considered rural.

Socioeconomic disparities that exist are related to poverty and lack of quality services. First, many times the rural population is too small to support experienced health care workers, hospitals, pharmacies, equipment, and new technologies. The resulting average cost per unit of service provided is significantly higher for rural populations than urban. For example, Arizona Health Care Cost Containment System (AHCCCS) covers 71% of rural hospital costs but only 57% if the hospital has less than 75 inpatient beds. Compare this to metropolitan hospitals reimbursement of 95% and it is evident rural hospitals are not adequately reimbursed (Arizona Hospital & Healthcare Association, 2002).

Another socioeconomic disparity in rural environments is related to adequate healthcare coverage. Since rural communities are primarily comprised of small business owners, ranchers, and farmers, it is difficult for them to provide healthcare coverage for all their employees. There is a plethora of research that reveals the presence of socioeconomic disparities in rural regions is omnipresent nationwide, which is primarily due to a lack of adequate healthcare coverage (Blazer, Landerman, Fillenbaum, & Homer, 1995; Cornelius, Smith, & Simpson, 2002). It has been determined that 74% of rural small Arizona businesses do not offer employee healthcare coverage (West Group Research, 2000).

Shreffler (1996) examined access to health care services offered in rural settings since they have significantly declined due to rural hospital closures. These hospitals serve as the infrastructure of rural health care and when they are closed, other health services and providers are frequently lost. Shreffler examined multiple levels of the rural environment from an ecological perspective (micro, meso, exo, macro system levels) and the way in which the levels support, or do not support, access to health care. Shreffler found that adequate access to health care is an important determinant of health, and when rural hospitals close, implications for residents can be devastating. It is also important to note, rural health care services and the socioeconomic environment interact with one another, and over time, partially determine one another. This means the socioeconomic environment of a rural community determines which health care services it can afford to support. If a community is very poor socioeconomically, it will have a difficult time supporting a hospital, providers, and equipment if there is no way to pay for these services. However, the inverse is also true – industries, which are the driving force behind a community's economic climate, will not be encouraged to develop a business in a rural community if it lacks basic health care services. Industries typically pay attention to these factors for two reasons: 1) safety of their workers and 2) recruitment and retention of workers. All of this results in a vicious cycle that contribute to poverty of people and poverty of services.

It is through effective energy and resource use in the environment that the rural care services system adapts to the environment at all levels (i.e. micro, meso, exo, and macro). Lastly, when adaptation is successful, the health care system not only survives

but contributes to the health of the community. However, when resources are exceeded or depleted and adaptation does not occur, the rural health care system does not survive.

Lack of insurance, inadequate employment and cost of health care are the key barriers to accessing primary care in rural settings. Therefore, it can be concluded that socioeconomic disparities create more of a problem than geographical distance for rural residents' access to care and service utilization. Since adequate access to health care is one determinant of health and these disparities exist, it can be deduced that the health status of rural populations suffers due to barriers in access to care, quality, and service utilization.

Addressing Quality in Rural Communities

Several agencies have stepped forward in an attempt to aid rural health systems to comply with the emerging quality and safety policy. The AHRQ is the lead federal agency charged with measuring and improving healthcare quality and safety in America. AHRQ's mission is "to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans" (AHRQ, 2007). This organization's research has supported the examination of various aspects of organization, delivery, and financing of health care in rural America. To aid in "bridging the quality chasm", AHRQ facilitates and conducts user-driven research that meets the needs of the agency's customers, translates research and evidence into practice that can be used to improve healthcare, and works with users to ensure that research results in measurable improvement. This is accomplished through involving a wide range of topics, including quality measurement, quality improvement strategies, and error reporting systems (Burstin & Wakefield, 2004).

Despite AHRQ's valiant efforts to address the quality of rural healthcare, these questions remain: Are these measures relevant and of value to consumers of rural health services? Are these measures valid and reliable across the rural care continuum? In order to accurately and comprehensively address rural health care quality and safety, healthcare providers need to know their individual community, due to the heterogeneous nature of rural America (IOM, 2004). Questions that must be addressed include: 1) community characterization based on federal definitions of rurality; 2) characteristics of rural populations including age, ethnicity, socioeconomic status, and definition of health; 3) characteristics of local rural health delivery system including ratio of providers to patients and care continuum; and 4) local health disparities.

Limitations

As previously established, rural communities must comply with the mainstream healthcare quality and safety initiatives in order to maintain their viability in the future. IOM (2004) has done a good job of aiding rural communities to bring urban quality issues down to the rural level; however there is much more work to be done in order to adequately serve rural communities. Due to the heterogeneity inherent to rural communities, a one-size-fits-all approach will not be conducive to individual community needs. Embarking on such an endeavor without first gaining insight into the makeup of the community may prove to be futile. Calico et al. (2003) proposes a general framework for development of rural quality performance improvement. Characteristics should include: 1) patient centeredness, 2) sense of ownership by users and an engaged community, 3) collaboration among providers, 4) quality improvement initiatives that are

relevant to the rural provider, 5) attention to the performance of the total organization, 6) integration across the continuum of care, 7) effective information technology, 8) adequate data and information for management and improvement; data-driven decision-making, 9) community orientation, 10) rural-appropriate measures of clinical processes and outcomes, functional status, patient satisfaction, organizational performance, and community health status, 11) investment in technology, and 12) long-term sustainability.

In order to attain these characteristics rural healthcare leaders must first have a working knowledge of the community on several levels to be successful at quality and safety improvement endeavors. The health of populations and communities do not occur in isolation; thus, health is a multidimensional issue with the community's health being a matter for the entire community, not just the health care professionals.

Conclusion

This chapter has attempted to define rural according to Census Bureau and OMB definitions, with HRSAs definition of border. Although these agencies have attempted to further differentiate this definition, it is necessary to clarify that rural areas contain an abounding diversity of land and people that cannot be fairly characterized by any one definition (Leight, 2003). Clearly, a new definition needs to be developed that represents both the demographic and health data of rural populations. This is necessary since it would make a substantive difference in rural health care policy and fund distribution.

Characteristics of the rural milieu were outlined as the majority of rural residents tend to be elderly, White, poor, and uninsured. However, a growing number of minorities comprise rural environments and are expected to continue their migration into

rural areas. Rural residents tend to describe their health as fair to poor and participate less in health promotion disease prevention activities, when compared to their urban counterparts.

The rural health delivery system was discussed and several factors were identified to affect the system including: 1) poverty, 2) inadequate transportation, 3) large geographical distances, 4) an aging population base, and 4) rural economic decline. All of these factors adversely affect the rural continuum of care, creating health care disparities. Rural health care disparities exist in all three areas examined by the IOM (2002): access to care, service utilization, and quality of care. The principal health care disparities established through this paper include not only geographical disparities but also socioeconomic. It is through the geographical and socioeconomic factors found in rural environments that residents are unable to access and utilize care.

The purpose of this study was to establish the need for rural nurses to be proactive in knowing their community, to ensure the provision of culturally competent and valuable health services, while empowering the community to increase awareness of the entire community's health issues. Rural nursing key concepts, as proposed by Lee (1998), Lee and Winters (2006), and Bushy (2000) attempts to provide this knowledge to nurses; however, it is uncertain whether these key concepts hold true for all rural communities, primarily a rural Southeastern Arizona border community.

CHAPTER TWO

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

This chapter will seek to discuss the importance of rural healthcare providers knowing their community for the basis of providing high quality, safe, and culturally competent care. Methods of gaining this community knowledge through knowledge sharing with the community will be discussed with the proposition of using community capacity theory. Knowledge to be gained includes characteristics of the local environment and population from various constructs. This results not only in an informed community, but a community that becomes engaged and connected, while gaining the tools to be proactive in promoting the health and well-being of the community as a whole.

Theoretical Foundation

In order for community capacity to be adequately defined, it must be clarified what is mean by "community". According to Stoner, Magilvy, & Schultz (1992) "community" is defined by a physical area in which members interact to meet common needs and goals. This interaction adds an additional dimension to "community" as an evolving social entity that is more than a defined boundary or the sum of its population. Understanding "community" is essential as communities have the potential to offer a rich resource for change. They can be mobilized to identify, plan, channel resources, and undertake effective action for health promotion and health-enhancing social change (Norton, McLeroy, Burdine, Felix, & Dorsey, 2002).

Community Capacity

There is a plethora of theoretical literature regarding the concept of community capacity of which it is important to note a gold standard of measuring or defining is lacking. For the purposes of this paper, community capacity focuses on the valuable attributes of both individuals and the social structures that exist in communities. These attributes entail a set of dynamic community traits, resources, and associational patterns that are necessary for community building and health improvement. Structural networks and processes that nurture and maintain these traits, resources, and patterns are also inherent to community capacity. Of equal importance are the perceptions, skills, and resources of individuals that are channeled through these social structures (Norton et al., 2002). Goodman, Speers, McLeroy, Fawcett, Kegler, Parker, Smith, Sterling, & Wallerstein (1998) provide two additional definitions of community capacity: 1) the characteristics of communities that affect their ability to identify, mobilize, and address social and public health problems and 2) the cultivation and use of transferable knowledge, skills, systems, and resources that affect community- and individual-level changes consistent with public health-related goals and objectives (p. 259). The favored, all-encompassing definition of community capacity includes the influences of context, desired outcomes, and methods to build capacity:

> "Community capacity is the interaction of human capital, organization resources, and social capital existing within a given community that can be leveraged to solve collective problems and improve or maintain the well being of that community. It may operate through informal social processes and/or organized

efforts by individuals, organizations, and social networks that exist among them and between them and the larger systems of which the community is a part" (Chaskin, Brown, Venkatesh, & Vidal, 2001, p. 7).

Importance of Community Capacity

It is evident, by these definitions, the important role community capacity plays in assessing, planning, implementing, and evaluating health initiatives within communities. The concept of community capacity emerged when public health experts began to view the community as the problem and the solution to common health problems. An ecological framework was proposed that elicited the interdependence of people, institutions, services, and the broader social and political environments. This lead to an examination of the nature and extent of social relationships that exist within communities and the presence of community factors that may affect the ability of communities to mobilize to address systemic problems (IOM, 1988).

It is important to note that community capacity has the ability to not only achieve community health improvement, but also improve or even instigate community development. This community development is the introduction of the community becoming more capable of solving their own health problems at both the individual and societal levels (Norton et al., 2002).

Dimensions of Community Capacity

Multiple frameworks exist in the theoretical literature outlining community capacity, of which there is tremendous overlap. The works of Goodman et al. (1998) and Norton et al. (2002) have been chosen for discussion here.

The framework outlined by Goodman et al. (1998) encompasses the following dimensions: Participation and leadership, skills, resources, social and interorganizational networks, sense of community, understanding of community history, community power, community values, and critical reflection. For associated subdimensions see Appendix A.

The framework outlined by Norton et al. (2002) was developed using a combination of nouns in the literature. These include: community competence (Cottrell, 1976), public capital (Harwood Group, 1996), community capacity (Goodman et al. 1998; Easterling et al., 1998; Chaskin et al., 2001), civic capital (National Civic League, 1999), and social capital (Saguaro Seminar, 2001). These combinations lead to the following dimensions being proposed: Skills and resources, nature of social relationships, structures and mechanisms for community dialogue, leadership, civic participation, value system, and learning culture. For associated subdimensions see Appendix B.

Both of these frameworks have many similarities; however, Goodman et al. (1998) mentions critical reflection which is lost in the framework proposed by Norton et al. (2002). Although Norton et al. (2002) includes critical reflection in the learning culture dimension, it is felt critical reflection encompasses much more than learning. Critical reflection demands not only understanding and logical reasoning of others' ideas, actions, and the forces within the community; but requires intense scrutiny of these factors and the potential ambiguity inherent to them. Critical reflection also requires self-analysis and awareness at both the individual and institutional levels (Goodman et al, 1998). With

taking this clarification into consideration, this study uses Norton et al.'s work to evaluate community capacity of a rural southeastern Arizona border community.

Link of Theory to Project

Rural nursing concepts (Lee, 1998; Lee & Winters, 2006; Bushy, 2000), rural health delivery literature (Calico, Dillard, Moscovice, & Wakefield, 2003; Moscovice & Rosenblatt, 2000), and healthcare quality and safety literature (Burstin & Wakefield, 2004; IOM, 2000; 2001; 2002; 2004) all point to the disparaged nature of rural America and the need for fundamental change in order to reduce health risks and ensure a secure and healthy future for rural residents. The primary stalemate in achieving these goals for rural America is attributed to the heterogeneity inherent to rural communities. This means a one-size-fits-all approach will not be conducive to individual community needs. Embarking on any community health endeavor without first gaining insight into the makeup of the community may prove to be futile.

It is necessary for rural health care leaders to have a working knowledge of the community on several levels to be successful at building valuable and sustainable community health initiatives. The health of populations and communities do not occur in isolation; thus, health is a multidimensional issue, a matter for the entire community, not just the health care professionals.

Literature Review: Key Concepts of Rural Nursing

Since nursing is a social experience guided by the relationship between the profession and the society in which it is practiced, a working understanding of rural nursing and the people served is critical in the development of a theory base for rural

professional practice (Bushy, 2000). As nursing practitioners, educators, and researchers, grand nursing theory guides nursing wherever it is practiced. Specific guidelines for rural nursing can be developed through middle-range theory. This can be accomplished through a thorough understanding of the rural context of practice and key concepts found in rural environments.

There is ongoing debate as to whether rural nursing should be considered a specialty or whether it is just the basic discipline of nursing that is being practiced in rural communities (Bushy, 2000). It is the opinion of the author of this study that rural nurses are indeed practicing the basic discipline of nursing, however, the context of practice in which they do this is central to understanding the core of rural nursing. It is also believed by the author that advanced practice nurses need extensive socialization and preparation to practice in the rural milieu since the context of practice can vary from one rural community to another. This literature review will seek to explore the extensive literature related to rural nursing and create dialogue regarding the intricacies of rural nursing practice; making rural nursing separate and distinct from the general discipline of nursing. Scharff (1987) wrote about the core of rural nursing not being different from the general discipline of nursing. However, it's the "intersections or meeting points at which nursing extends its practice into the domains of other professions; the dimensions, that is, the philosophy, responsibilities, functions, roles, skills, and boundaries, which respond to new and growing needs and demands from society, appear to be very distinct for rural nursing practice" (p. 14). More recently, Scharff (1998) wrote, "Rural nursing practice, be it hospital practice, private practice, or community health practice, is distinctive in its

nature and scope from the practice of nursing in urban settings. It is distinctive in its boundaries, intersections, dimensions, and even in its core" (p. 20).

The goal of developing a middle-range theory for rural nursing is to guide practice and research. This theory would facilitate development of evidence-based nursing interventions that are relevant to the diversity found in rural environments and populations. As a result, a middle-range theory for rural nursing will increase the theoretical foundation of rural nursing practice which will aid in enhancing the health status of Americans living in rural communities, decreasing the detrimental affect disparities currently have in these communities (Bushy, 2000).

Core Nursing Concepts and Application to Rural Settings

The problem with examining nursing in rural environments is the "majority of the work is based on vignettes and anecdotes, using inductive approaches" (Bushy, p. 34, 2000). Also, a great deal of the data is based on the experiences of only a few individuals in limited areas of practice throughout the US. This has been the primary set back in developing a middle-range theory for rural nursing. Another setback is the diversity inherent to rural nursing practice and environments; data that fits in one part of the US may not fit with rural nursing practice nationally, or even, internationally – again a return to context of practice (Bushy, 2000).

Four concepts are common in all grand nursing theories: person, environment, health, and nursing. When developing a nursing theory, one must examine all four of these concepts and how they interrelate with one another. Bushy (p. 35, 2000) developed

a table with the four core concepts of nursing theory and how they can be applied to nursing in rural environments.

Concept	General themes	Rural dimensions
Person	- Genetic and biological variations - Human relationships - Values/views about humans at birth and death - Who/which are valued most/least (individuals, related or nonrelated support systems) - Human focus (doing, being, becoming) - Spiritual relationship (control, subordination, harmony)	- Diversity - Multicultural population - Familiarity among locals - Preference for care by known person - Newcomer (outsider)/old-timer (insider) dichotomy
Environment	- Physical/social/cultural - Values formation and orientation - Time orientation (past, present, future) - Belief systems and manifestations	- Greater space between places - Less dense population - Diverse geographic terrain - Orientation to the natural environment - Occupations and recreation seasonal and cyclical
Health	- Definitions of health and illness - Major beliefs - Worldview - Healing practices - Health and illness behaviors - Taboos, rituals, rites of passage - Health care systems, formal and informal	- Ability to work - Less emphasis on physical, more on spiritual - Varies by culture - Greater reliance on self-care and informal systems
Nursing	- The professional nurse - Nurse-client interactions - Caring concepts and practices - Provider culture	- Lack of anonymity in the community - Familiarity with clients - Generalist nursing role that overlaps with roles of other health disciplines (role diffusion) - Multiple roles in the community

Table 1: Core Nursing Concepts: Application to Rural Settings

From the four key nursing concepts and how they relate to rural settings, Lee (1998) and Bushy (2000) developed relational statements. These have been proposed for the emerging middle-range theory for nursing in the rural environment and are still being tested.

1. Rural dwellers tend to be independent and self-reliant in health-seeking behaviors. In the rural environment, help is usually sought by residents through informal rather than formal systems (Bushy, 2000). When formal systems are utilized, rural dwellers tend to resist accepting help or services from those seen as outsiders and utilize formal networks less frequently than informal networks (Lee, 1998).
2. Nurses in rural communities face much greater role diffusion than counterparts in urban settings. Nursing practice is significantly affected by a lack of anonymity within the community.
3. Nurses in the rural practice environment frequently are under pressure to assume some of the functions that traditionally are in the realm of other disciplines. These can be as diverse as being expected to practice medicine when a physician is absent and being asked to shovel snow when the groundskeeper is unable to get to the hospital.
4. Nurses in rural communities report a sense of always "being on duty". Because they lack the anonymity allowed urban counterparts, rural nurses are sought out by neighbors and friends as sources of health-related information every conceivable context, including church, school, and community events (Bushy, 2000).
5. Rural dwellers define health primarily as the ability to work, be productive, to do usual tasks. Rural persons place little emphasis on the comfort, cosmetic, and life-prolonging aspects of health. One is viewed healthy when able to function

> and be productive in one's work role. More specifically, rural dwellers admitted that pain is often tolerated, often for long periods, as long as it does not interfere with the ability to function (Lee, 1998).

It is important to remember that these relational statements are important in refining a theory for nursing in rural environments, however, more testing and validation is needed before they can be applied across the diverse rural continuum. The need for such a theory has been outlined with several key concepts that are distinct to rural nursing practice. The remainder of this chapter is dedicated to building a definition of rural nursing.

Rural Nursing Examined

According to Bushy (2000), rural nursing practice is different from urban practice and it is perverse to suppose that rural health care and nursing practice will mirror that in urban environments. She goes on to explain that rural nursing is especially different from what most nursing students have experienced in their education. This can pose huge barriers to practice to an urban prepared or new graduate nurse working as a rural nurse, regardless of skill level. For example, nursing in a rural hospital does not require the specialized care that is often present in urban hospitals. Rural nurses are expected to function as generalists, taking care of patients from birth to end-of-life with a wide range of health problems and disease states. It is also imperative for rural nurses to have a well-grounded community and public health background (Hanson, 1999) to better serve the rural population, which, as mentioned in Chapter One, has difficulty accessing and utilizing care due to geographical and socioeconomic disparities.

Of special significance in the discussion of rural nursing is that rural nurses are invariably well-known in the community, outside of their working environment. The rural nurse is often times a revered member of the community, but can also fall under public scrutiny, even when not in the work environment. The resultant lack of anonymity will be discussed later in this chapter, but is significant enough that it warrants mention now, since this is one of the hallmark characteristics of rural nursing. Generally, rural nurses are known by their patients in a variety of roles throughout the community and as a result rural nurses know their patients' roles as well (Long & Weinert, 1998)

Context of Practice

Context of practice affects every aspect of the general discipline of nursing. It aids in defining nursing for each individual community and is reliant on numerous factors, including 1) politics of the community, 2) socioeconomics, 3) rural culture, and 4) ethnicities within the community. It is these factors that set the tone for healthcare within rural communities. Another way of stating this is: Rural nursing is a reflection of the environment in which it exists.

In order for the rural nurse to better understand the context in which he/she is working it is useful to perform an assessment of the community. This community assessment lays out the broad healthcare strengths and weaknesses of the community. Things to consider include the decision-makers within the community, demographics of the area, predominant age group of the community to better assess needed services, special diseases endemic to the region, and social/health problems including substance abuse, mental illness, and teenage pregnancy rates. Rural nurses need to completely

immerse themselves into the culture of the rural milieu where they practice to gain a better perception of health beliefs and values within the community (Hanson, 1999), hence, understand the context in which they practice.

Key Concepts

Rural nursing theorist Lee (1998) and Lee & Winters (2006) identified several key concepts that are essential in understanding what rural nursing is comprised of. These concepts also are important in providing care for persons living in rural environments since they often times shape a patients access to care, service utilization, and the quality of health care provided. These factors include: 1) distance, 2) isolation, 3) lack of anonymity, 4) familiarity, 5) old-timer, 6) newcomer, 7) insider, 8) outsider, 9) self-reliance, 10) health resources, and 11) informal networks. These will each be discussed below.

Distance.

Distance "implies a degree of separation between two or more entities" (Henson, Sadler, & Walton, p. 51, 1998). This becomes a key concept in rural nursing since the distance a patient lives from the health care facility, often influences the deliverance and receiving of care. Essential attributes to consider when discussing distance as it relates to providing health care in rural environments includes: 1) mileage, 2) time, and 3) perception. Mileage and time are objective measurements of distance, while the way in which distance is perceived is subjective. Depending on the resources and perceptions of the rural patient, overcoming distance may be difficult. It is imperative for rural nurses to

assess the influence of distance on patients and their care since nurses can help facilitate resource utilization to reduce the impact of distance on their patients (Lee, 1998).

Isolation.

There are varying types of isolation, including: 1) geographic, 2) social, and 3) professional. All three of these affect rural nursing in differing ways. Geographic isolation affects health care quality, utilization, and access to patients. A consequence of geographic isolation is the potential for loss of health, limbs, or even life. Another consequence of isolation is deceased communication or interaction with other people, which leads to social isolation and for the rural nurse, professional isolation (Lee, Hollis, & McClain, 1998). It is the responsibility of the rural nurse and rural health care team to minimize the adverse outcomes of isolation on their patients and themselves through the creation and utilization of community resources.

Lack of anonymity.

Lack of anonymity is defined as "a condition in which one cannot remain nameless or unknown" (Lee, 1998; Lee & Winters, 2006). With regards to rural nursing, lack of anonymity suggests a lack of privacy about the rural nurses' personal life and the requirement of taking care of patients who are known outside of the client/nurse relationship. As mentioned previously, this is the hallmark of rural nursing and can be viewed as a positive or negative attribute. Lack of anonymity has been discussed in great detail and the affects it has on professional practice, Bushy (p. 36, 1991) states,

> "The small town's informal social structure, better known as the 'main street grapevine' facilitates professional disagreements becoming public knowledge ….

> Concerns related to confidentiality and anonymity….stem from the reality that most persons who live in a small community are (at least) fairly well acquainted. Many residents are blood relatives or have become a member of an extended family through marriage…"

Saunders (1992, p. 41-42) found in her research,

> "Nurses reported that everyone knows who you are and where you are and will call you. One nurse explained the only 'vacation' from nursing that she takes id during the 'lambing season'. She went on to explain when she did not answer her telephone while on vacation…'they'll drive out and come up to the lambing shed looking for me'. One nurse participant described a lack of anonymity during an emergency situation then 'they found me at the courthouse and asked me to hurry to the medical assistance facility'."

Hanson (p. 337, 1999) wrote,

> "Rural nurses have reported that interactions and chance meetings that occur in the grocery store or on the street give them a great deal of satisfaction and that this is an important dynamic for them to remain in their job."

In examining lack of anonymity, essential attributes have been identified. First, lack of anonymity requires the person experiencing it to be visible. Second, the person must be identifiable, and lastly the boundaries through which one functions are smaller resulting in diminished personal and professional boundaries (Lee, 1998; Lee & Winters, 2006).

It is so crucial for rural nurses to examine lack of anonymity on multiple levels. First, the patient perspective, rural patients may not feel comfortable seeking medical

treatment for controversial services for fear of their peers in the community finding out (Lee, 1998; Lee & Winters, 2006). This results in decreased service utilization. It is imperative for rural nurses to maintain confidentiality of all patient interactions to prevent this behavior from being perpetuated.

The second approach in examining lack of anonymity is how it affects professional practice. Long and Weinert (p. 120, 1989) stated, "healthcare providers must deal with lack of anonymity". Lee (1998) has mentioned possible ways in which this concept affects rural nursing, although research in this area is still needed. These include: accountability, influence on care provided, and interference with objective patient assessment, provision of better quality care, and nurse retention and turnover.

Familiarity.

Similar to lack of anonymity, familiarity is an ever present feature found in rural nursing; hence, it has an enormous impact on health care service provision and utilization. The defining attributes of familiarity are identified as a "friendly relationship or close acquaintance, intimacy, informality, and exhibited familiarity is welcome or unwelcome depending upon the perceptions of the receiver" (McNeely & Shreffler, p. 98, 1998).

Davidson (1990) wrote an editorial on how familiarity can enhance medical practice from a physician assistants' perspective. He wrote, "The title 'doctor' defines a formal relationship between a physician and a patient. However, physician assistants do not have such a title and often use their first names. This familiarity is often reciprocated and it truly enhances my ability to provide care…and gives them permission to confide in

me. When patients call and ask for 'Jim', they know a friend will answer the phone" (p. 16).

Davis and Droes (1993) were the first to agree with Davidson (1990) through citing the in depth interpersonal knowledge of familiarity as a major characteristic of rural community health nursing and it is this interpersonal knowledge that enhances the effectiveness of rural providers.

> "Knowing your patient, knowing the life they lead, their usual habits, that helps me a lot in my approach. I think my patients are more comfortable. You start with a larger information base. You get to know the patients well and grow fond of them; become like family…you can focus more on their total care because you get to know them like a person. With some patients, you start with a level of respect that has already been earned in the past" (Davis & Droes, p. 166, 1993).

McNeely & Shreffler (p. 96, 1998) go on to say,

> "This use of the freedom of speech to use one's first name implies that informality and friendship are indeed important components of the concept of familiarity."

It is also important to remember that rural patients are friends, neighbors, or relatives to the people who provide health care in the community. Therefore, when health care services are provided in the same environment, it results in highly personal care due to provider familiarity with their patients (Hanson, 1999).

Old-timer/newcomer and insider/outsider phenomena.

Prior to Lee (1998) and the work of her nursing graduate students (Caniparoli, 1998; Sutermaster, 1998; Myers, 1998; Bailey, 1998) the phenomena of old-

timer/newcomer and insider/outsider was discussed throughout rural literature, however, these theorists were the ones that created well-developed definitions of each. This was done through extensive literature reviews of various disciplines, including nursing, sociology, anthropology, education, business, philosophy, literature, and art. Lee (1998) then compiled these definitions to help build key concepts in her rural nursing theory. Following are detailed explanations of each concept and how it relates to rural nursing.

Old-timer.

The definition of old-timer in rural communities is still being explored by rural nursing theorists. However, the beginning stages of definition development have been underway and the following are key components of old-timer status in the rural milieu. Weinert and Long (1987) and Long and Weinert (1989) were the first to publish the concept of old-timer, and newcomer to be discussed next. Through their studies on rural dwellers perceptions of health care, they found the following definition of old-timer,

> "If grandparents or parents settled in Montana, they most generally described themselves as a 'native'. If they did not have these roots in the state but had lived in Montana for 20 years or more, there was a 50-50 split between describing themselves as a 'native' or an 'old-timer' (Long & Weinert, p. 454, 1989).

They went on to quote a rancher that explained the difference between old-timers and newcomers in the following way,

> "Around here, a 'newcomer' is someone who's lived here from about three months to four years; an old-timer is someone who's ranched here at least one generation" (p. 455).

According to Caniparoli (1998), twenty years of residence in a rural area may be the operative number. Anyone who has lived less than twenty in the community is viewed as a newcomer. Caniparioli (1998) also created defining attributes of old-timer status. She states old-timers are typically of an older age, and lived in a specified area for a certain amount of time. This amount of time is dependent on the community involvement of the individual and established relationships. This establishment of old-timer status within a rural community serves the purpose of setting individuals apart from the rest of the community. This may lead to positive or negative views of the particular person, depending on the role of the viewer.

It is important to define old-timer in regards to rural nursing since it is through this key concept that social networks are set up in rural communities. As Weinert and Long (1987) stated,

> "Rural dwellers used the concepts of 'old-timer' and 'newcomer' as a framework to organized their social interactions, their relationships within the community and were important to their 'view of the social environment'" (p. 453).

Social networks within rural communities are the driving force behind health care and can drastically affect a newcomer's acceptance into the community, hence, success as a healthcare provider.

Newcomer.

As mentioned earlier, Weinert and Long (1987) are pioneers in defining the old-timer/newcomer concepts in relation to rural nursing. They acknowledge these two

concepts are related yet opposing, and offer three main descriptions for newcomer found throughout their research. All three of these descriptions dealt with the time lived within the community and are as follows: 1) three months to four years, 2) more than ten years but less than twenty, 3) full integration into the community could not occur until the newcomer lived in the area for at least ten years.

It was also determined by Long and Weinert (1987) that acceptance into the community was dependent upon family history. This is important to rural nurses since newcomers who are professionals (nurses) will not be relied upon or even utilized until they are accepted. To go along with this thought is Bushy's (1993) research that discovered rural residents have a shared history and are well-known to each other and tend to interact with people who are similar to themselves, in regards to rurality. Bushy (1993) states, "The concept of newcomer implies that long-time residents are reluctant to establish close ties with new persons entering their community" (p. 190).

Sutermaster (1998) describes three key factors in defining the newcomer concept. These include: 1) the person or family must have newly arrived/moved to the area, 2) they are unaware of the community's history and social structure which includes the unwritten rules that dictate the culture of the community, and 3) their presence may lead to changes within the population which may lead to uncertainty in the community, hence threatened security. These factors can be detrimental to a new nurse in a rural community, especially a nurse practitioner (NP) that is trying to build a clinic to serve the health care needs of the population. If the population does not accept the NP, the success

of the practice will be at stake. This further undermines the need and provision of health care services in rural environments.

Insider.

Long and Weinert (1989) have described the term 'insider' as a key concept in understanding rural health care needs and nursing care provided. They cite this concept as relating to how rural communities view relationships and organize their views of the community. It is essential to truly understand the importance of this concept as it relates to rural nursing since health care providers must gain acceptance of the community in order to provide health care to these populations.

Long (1993) outlines an insider as someone "who can be trusted to understand the social context of the health care problem" (p. 124). In addition to this definition, Weinert and Long (1987) cite several variables in determining a person's insider status. These include: 1) length of residence, 2) family history, and 3) type of occupation. Key attributes to the definition of insider are: 1) having access to privileged information, 2) an awareness of implicit assumptions and social context, 3) member of a group, and 4) a long-time occupant of the community (Myers, 1998).

It is important for the rural nurse to understand the consequences of such status in the rural community. First, being an insider allows the rural nurse to be privy to power. This power is gained through having information that others lack. Second, insider status allows the rural nurse to have a reserved social position that is often times not available to other community members. The third consequence of being 'inside' is the commitment

to a group. Lastly, being an insider creates a lack of objectivity when outside of the group (Myers, 1998).

It is important for the rural nurse that is migrating into a rural community to identify and form a liaison with an insider within the community. This is paramount since the liaison can inform the rural provider of the social context and assumptions of the community. But most importantly, it is important for this liaison to help the rural nurse to gain acceptance to ensure the nurse will be able to provide care that is viewed as essential and valuable (Myers, 1998).

Outsider.

According to Bailey (1998), outsiders lack a comprehension of the social context, beliefs, rituals, customs, and history of the community. The result of being an outsider is the exclusion of access to information and knowledge, lack of acceptance, not being recognized, isolation, and distrusted by community members. It is important to remember that health care providers, specifically rural nurses, are often times considered outsiders when they first migrate into a new community. As Long & Weinert (1989) noted, the concepts of insider/outsider can be applied to all health care professionals in rural areas attempting to gain acceptance. Bailey (1998) goes on to describe the essential attributes to being an outsider as: 1) differentness in terms of cultural orientation, standards, lifestyle, education, religion, occupation, social status, world view, interests, or experience; 2) unfamiliarity with the community; 3) unconnectedness or having no family ties or other personal ties. Long (1988) also defines several factors that are central

in determining if a member of the community is an outsider: 1) cultural orientation, 2) family ties, 3) occupation, and 4) length of residence in area.

Due to these factors that make up the concept of outsider, it is important for the rural nurse to understand the affects it can have on his/her practice. It is imperative for rural nurses to seek out the community and familiarize themselves with local perceptions of health and unique community needs to decrease their chances of being kept an outsider and to be accepted as an insider. This will facilitate acceptance of the provider and utilization of health care services in rural environments, as well as, enhance access to care.

Self-reliance.

Long & Weinert (1989) defined the concept of self-reliance as "the desire to do for oneself and care for oneself" (p. 119). They also stated this concept is innermost in accepting and creating health care services for rural dwellers. This was discovered through the phenomena of rural dwellers being, resistant to care from persons viewed as outsiders, they seek health care information and assistance from local, and often informal sources, and view the individual as responsible for health knowledge and care. Bushy (1991) also found that rural families have a propensity to be more self-reliant, doing more services for themselves, and relying on family and rural community resources for assistance and social support.

This concept of self-reliance has been described as a value important throughout Western civilization. It has especially been shown, more often, to be a common trait in rural people. In the development of self-reliance, individuals progress along diverse

paths, experiencing gains, losses, and changes according to the framework of their personalities, cultural environment, and life-course events (Chafey, Sullivan, & Shannon, 1998).

Other concepts that are closely related to self-reliance include independence, self-determination, individuality, and privacy. These have all been used throughout nursing literature regarding rural nursing to characterize the cultural values and attitudes of rural people (Chafey et al., 1998). Understanding this key trait of rural populations is imperative in the creation of health care services, and thus the provision, throughout the spectrum of rural environments and people.

Health resources.

Resources are: "properties, resorts, or assets that are finite by nature and are made available for use by populations through an allocation process. Resources are accessed and used in response to a population's or individual's motivation for need satisfaction" (Ballantyne, 1998, p. 182). Therefore, three elements makeup resources, including: 1) allocation, 2) accessibility, and 3) utilization. These three are interconnected through bidirectional energy from each other.

For rural dwellers, accessibility and utilization of an allocated resource depends on a number of factors. In most rural health care networks, the providers and nurses are considered generalists. Although they often have a broad spectrum of knowledge, most are lacking specialty services. If it is determined, either by the patient with the support of their social network or the rural health care provider that specialty care is needed, it may need to be accessed outside of the rural community. If the patient is motivated to seek

medical care outside of the local system, factors such as transportation, distance, inclement weather, and finances become important issues and can have a detrimental effect on outcomes (Ballantyne, 1998).

Health care resources are deficient in much of rural America due to maldistribution of health professionals and barriers to accessing care (IOM, 2002). For this reason, rural nurses need to increase the rural populations' awareness of allocated resources not only in their community but also at regional and national levels. It is also important for rural nurses to encourage improved service allocation, accessibility, and utilization to enhance the health and well-being of their communities. If suitable services and referrals are facilitated at each level, that is locally, regionally, and nationally, the stability will be maintained between allocation, accessibility, and utilization of health resources for rural communities (Ballantyne, 1998).

Informal networks.

As discussed with self-reliance, rural dwellers tend to avoid formal health services for various reasons. Often times the rural dweller will turn to informal networks to help in decision-making regarding health and wellness (Weinert & Long, 1991). Informal networks are present throughout every aspect of human life and play an integral role in our existence. Often times these networks in rural America are seen as safety nets for rural clients that are "falling through the cracks" of formal health care provision (Grossman & McNerney, 1998).

The key components that make up informal networks are: 1) volunteer, 2) information exchange, 3) support, and 4) guidance. Usually these networks are made up

of family members, friends, coworkers, and neighbors. These people are considered the volunteers because they typically offer assistance free of charge due to a bond they have with the patient. Information exchange is the sharing of information between members of the informal network. Support is what is provided within the network and can either be emotional or physical. Guidance is also provided by the network in the form of advice, consultation, and information regarding availability of resources, referral to health care providers, and sources of alternative treatments (Grossman & McNerney, 1998).

These networks have been found to have a significant value to rural nursing practice. Rural nurses need to realize the value of informal networks as sources of support and guidance for their patients. These networks can be used by nurses to disseminate and receive information regarding the health needs and perceptions of the community, leading to the provision of holistic nursing care to rural populations (Grossman & McNerney, 1998).

Limitations of Current Rural Research

Lee (1998) and Lee and Winters (2006) rural nursing theory was generated in rural Montana near the US-Canada border. This theory has thus far not been tested outside the original environment. The location of this project, rural Arizona community, near the US-Mexico border, poses an interesting contrast to the proposed theory widely being used today. From this study, it is hoped not only that healthcare leaders in this community will be better equipped to provide relevant, high-quality, and safe services; but an informed community will emerge that gained the tools to be proactive in promoting the health and well-being of the community as a whole.

Conclusion

This chapter has attempted to define “community” as an evolving social entity in order to establish the need to assess community capacity; in the examination of understanding and prioritizing community health issues. Community capacity was outlined according to Goodman et al. (1998) and Norton et al. (2002). Dimensions for measuring community capacity were outlined, followed by an in depth discussion of rural nursing concepts. This review establishes the need for rural nurses to learn about their community with the forces at work. This review also established the need to scrutinize rural concepts as proposed by Lee (1998), Lee & Winters (2006), and Bushy (2000) for applicability across rural environments.

CHAPTER THREE

RESEARCH METHOD

This study used community assessment with ethnographic underpinnings, drawn from General Ethnographies and Nursing Studies in the State, also known as Project GENESIS, to evaluate a rural Southeastern Arizona border community's health. Community assessment was performed focusing on the following themes from the GENESIS model: health services, culture, and community. The community was engaged in identifying central themes to this rural community regarding health and utilization of health services. This was accomplished through focus group participation, key informant interviews, and participant observation. Lee (1998) and Lee & Winters (2006) rural nursing concepts were analyzed to determine if they hold true for a rural southeastern Arizona border community. This investigation is considered a community-based intervention due to the investigator aiding community groups and members to analyze community health and health behaviors; creating an awareness to build future health services and community wellness. The awareness of community on various interrelated levels by health care providers, plus an aware community, is central to the provision of culturally relevant, high quality, and safe health care.

Project GENESIS

Project GENESIS, an inductive research model, was developed in 1982 by Glittenberg, a professor of community health nursing and anthropology at the University of Colorado, School of Nursing. This methodology has been proposed to be essential in the development of rural nurses, but also the development and provision of high quality,

safe, culturally relevant healthcare. The GENESIS model "generates a comprehensive, holistic portrait of a community or an aggregate through secondary analysis of existing data and qualitative methods" (p. 223). This methodology is based on the long-standing assumptions found throughout nursing and public health literature that the health needs of a population are interrelated with the environmental, economic, social, educational, and cultural needs of that group (Schultz & Magilvy, 1988). Stoner et al. (1992) state that in order to solve community health problems, complex social, health, and quality of life issues must be addressed. In addition, the culture, values, and priorities of community members must be considered. This is the foundation from which community health issues should be addressed in rural communities to improve service provision, access to care, high quality care that is relevant and utilized.

The nature of the GENESIS methodology is heavy reliance on a collaborative effort between nurses and communities; having its basis on the belief that each community is unique and has established means to solve problems (Russell, Gregory, Wotton, Mordoch, & Counts, 1996). There are two primary assumptions central to the GENESIS method: 1) the health needs of a community and its residents are believed to be interrelated with the community's historical, environmental, economic, social, educational, and cultural strengths and needs; and 2) understanding individuals' perceptions of health-related concerns and their proposed solutions is thought to be imperative for designing and implementing effective health care delivery systems. Due to these assumptions, this model can be viewed as a community assessment that encompasses an evaluation of community capacity. Not only does GENESIS require the

nurse to establish the community as partner, but it raises awareness of the community's health with community members, potentially leading to prioritization and action on health needs (Holkup, Tripp-Reimer, Salois, Weinert, 2004). This partnership agrees that exploring characteristics of the local environment and population from various constructs is a community endeavor that requires professional support. This results in an informed community that gains the tools to be proactive in promoting the health and well-being of the community as a whole, while assessing the community's capacity to identify issues and implement change.

Epidemiologic and Ethnographic Approach

GENESIS involves the use of both ethnographic and epidemiologic approaches. Epidemiologic approaches entail the use of quantitative methods through secondary data analysis to define population demographics, morbidity and mortality -- through traditional indices. Despite the immense data sources available for this data analysis, there is some concern regarding the inadequacy of these gross indicators of community health and often times they are ecologically incomplete. For this reason, an ethnographic approach is a good fit and encompasses obtaining qualitative, subjective data that facilitates an understanding of residents' beliefs, perceptions, and values about their community's strengths and needs through key informant interviews and participant observation in the community (Russell et al., 1996). Together these approaches provide a well-rounded view of the community that aids in recommendation development to improve the health of the community.

Intersect of Project GENESIS and Community Capacity Theory

In this discussion of community-based intervention, GENESIS methods and community capacity, it is evident they all have a common ground: community engagement, connectedness, and action. These all support the building of valuable and sustainable community health programs with the common goal of decreasing disparities. Figure 1 outlines the dimensions of community capacity and how they fit into the GENESIS model. In examining Figure 1 (on next page), the intersect of dimensions and their presence in many constructs within the GENESIS model are evident. This establishes GENESIS as a community assessment and intervention method that subsequently evaluates community capacity. It also portrays the complex nature of communities and the need for such a multidimensional analysis to obtain a clear view of community and their capacity to acknowledge and prioritize health issues.

An examination of all the GENESIS constructs with community capacity dimensions within the community being studied was outside the scope of this investigation; although several of the constructs were focused on. These include culture, health services, and community. Through focusing on these constructs, the remaining constructs emerged in the investigation to a lesser degree. Through an examination of the focus constructs, the degrees of community capacity dimensions are expected to emerge.

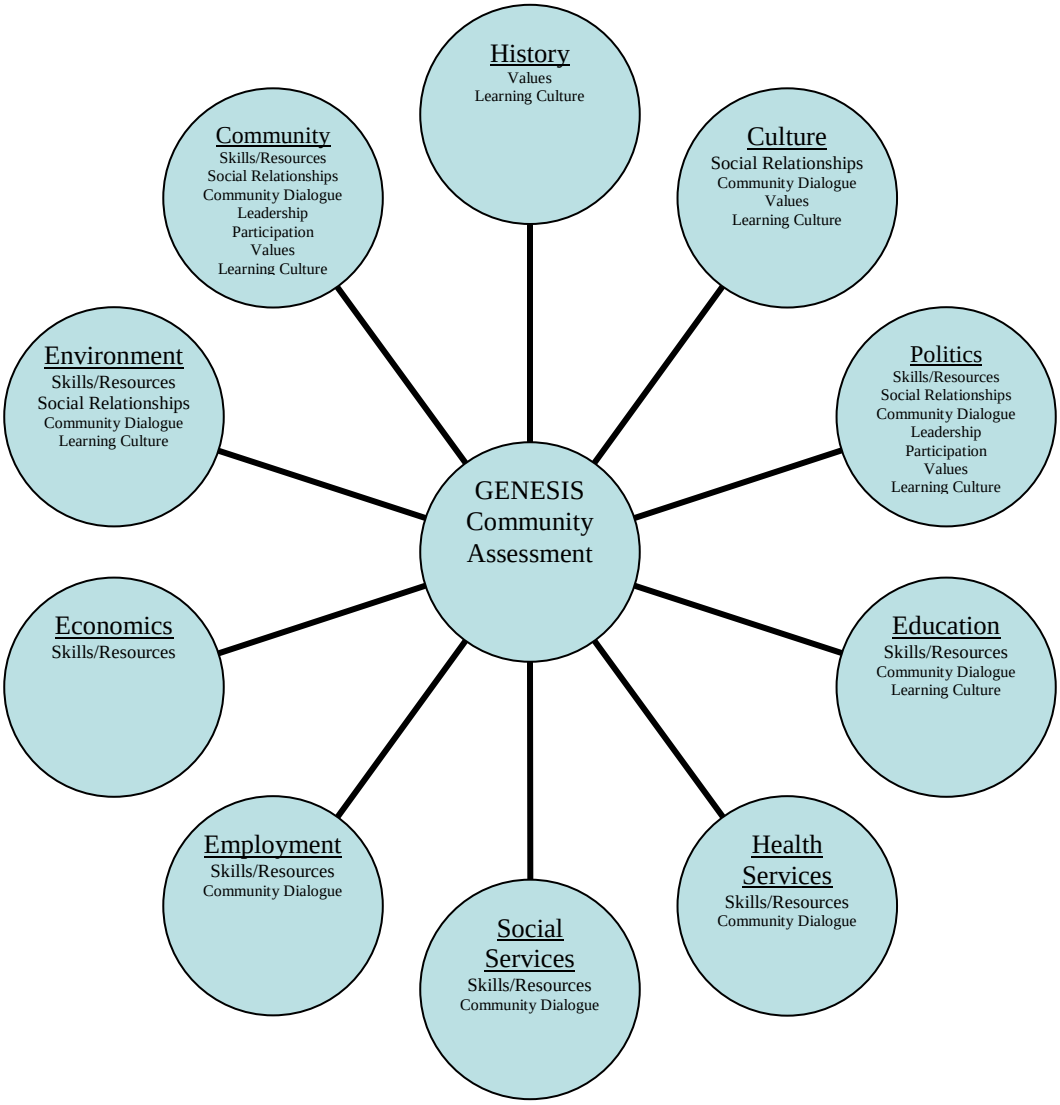

Figure 1: GENESIS Model Measuring Community Capacity

Synthesis of Professional Knowledge and Community Knowledge

As the previous discussion depicts, GENESIS allows the nurse to partner with the community for the shared goal of community assessment and intervention. With this partnership there are several factors that come into view that touch on the remainder of the GENESIS methodology. These factors include: 1) utility of presenting findings back

to the key informants, 2) conducting member checks and 3) professional knowledge versus community knowledge awareness.

Presentation of Findings and Member Checks

An essential component of GENESIS methodology is the evaluation of themes that emerged during data collection and analysis. This evaluation is carried out through taking the research findings back to the community for ensuring reliability and validation of findings; providing a mirror to the community. This can be accomplished through presentation of findings back to the key informants, a process known as member checks. Presenting the findings in such a way facilitates multiple processes within the GENESIS method and community capacity theory. These processes include: 1) synthesis of the process and methods, and reinforces future use of the research (Stoner et al., 1992); 2) allows key informants to provide their feedback on the accuracy of research findings. From this feedback, further analysis can be conducted to provide community evaluation of the research sampling, methods, data collection and analysis can be scrutinized for final reporting. 3) Community forums can also provide additional insight into community mobilization and thus capacity. If attendance is poor, it may indicate that people were unaware of the forum or were apathetic about its occurrence. Either way, attendance can elicit valuable information into community mobilization and connectedness (Russell et al., 1996). The intent of such endeavors is to gain insight into health values of the community. Many issues can be deduced from community involvement in all aspects of this project and their desire for community health and well-being. 4) The presenting of data to the key informants also brings data ownership into

question. This question is common in community-based research and interventions. Reason (1994) has asked the very question, "Who owns the knowledge, and thus who can define the reality?" The presenting of findings takes on a different meaning if the informants and community owns or co-owns the data. This ownership or co-ownership provides self-reflection while allowing the community members to have a voice if the findings are consistent with their realities. This aids in the goal of the community to then do something with the data. This component of presenting the findings back to the community is consistent with critical inquiry methods, and was determined to be outside the scope of this particular project by all committee members and the expert methods consultant. However, member checks were performed to ensure credibility. Future research could take on the critical inquiry approach, when it is deemed the community is receptive to such an endeavor.

Awareness of Professional Knowledge vs. Community Knowledge and Culture

As discussed above, the evaluation process is carried out through taking the research findings back to the participants through member checks for ensuring reliability and validation of findings. It is important for the nurse investigator to realize a disconnect may exist between the professional knowledge, perceptions, prioritization and the community's knowledge, perceptions, and prioritization of health issues. This is the primary reason community capacity must be evaluated. If capacity is found lacking, community development may need to precede implementation of programs (Norton et al., 2002). If capacity is adequate and prioritization is in conflict, the community is considered expert and their prioritization should dominate decisions made with input

from the investigator. For this reason, it was imperative for the investigator to be aware to this division when approaching community members and groups to ensure the success of community health programs (Leonard, 2004).

An example of a disconnect that can occur is: Professional knowledge indicates the smaller, poorer, and more isolated a rural community is, the more difficult it is to ensure availability of high-quality health services (IOM, 2004). This posits rural communities to have higher health risks and disparities (geographical distance, cultural values, and socioeconomic factors) (IOM, 2002). It was imperative for the investigator to have a sound knowledge of the community's perceptions of risk and disparity and whether this judged risk was perceived by those living in the community as these perceptions will guide prioritization and action on defined health issues. A question to be posed could simply be, "Do you feel that by living in a rural community you are in poorer health or have the potential to have poor health outcomes?" This question can generate dialogue on which factors generate risk or reduce it according to lived experiences.

Another component to consider when engaging communities is ethnic culture and community culture to ensure cultural competence. This is important specifically if a different language is spoken by the informant; every effort must be made to ensure the professional and community member can understand each other. This particular investigation did not include non-English speaking participants. The inclusion of non-English speaking participants is anticipated to be part of future work by this investigator. Cultural competence does not stop at just understanding language; the investigator must

understand the culture and the method in which to ask questions; paying attention to nonverbal communication and cultural norms of the community (Leonard, 2004).

Study Design

An exploratory community assessment design based on ethnographic principles was used to address the following research questions that address community health:

1. How does the community define health?
2. What enhances or impedes access to health services?
3. How does the community define quality of care?
4. What are viewed as the major health issues and needs?

Data collection included participant observation, key informant interviews, and focus groups.

Setting

The community assessment was conducted in a rural community in southeastern Arizona that is approximately 90 miles from the US-Mexico border. It is classified by the US Census Bureau as rural and by the OMB as noncore. The ethnographic principles utilized were gaining access, selection of focus group participants and key informants, participant observation, and iterative analysis (Glittenberg, 2001; Munhall, 2001). The principal investigator is an advanced practice nurse from the community under study, so access had been established in a general way. Since the investigator had a pre-existing emic viewpoint, an outside observer was used to provide neutrality and objectivity.

Sample

Data were sampled from various sources, including focus group participation, key informant interview, participant observation, and secondary data sources. Secondary data sources included community history and community statistics from the US Census Bureau, Centers for Disease Control and Prevention, and Department of Health and Human Services Vital Statistics. This data describes the community both demographically and by disease burden while establishing context at the local, county, state, and national levels.

Criteria for Participant Selection

A purposive sampling technique (Lincoln & Guba, 1989) was used to select key informants for participation in two focus groups from the Willcox community. One focus group consisted of those community members that fell within the 20 percent market share held by the local health services sector; the second group consisted of the 80 percent that travel outside the community for health services (Dixon Hughes, 2008). Determination of which group the informant was assigned was based on self-report. This enhanced the emic viewpoint sought in this study. Both of the groups were representative of the community demographic data, to be discussed below, with a total of ten participants allowed per focus group session.

Sampling at the beginning of the study increased the ecological validity and was concerned not only with the selection of key informants that could give insight into the phenomena under study, but also the selection of place and timing of data collection. It is an ongoing process occurring at those points during the fieldwork, when people, places,

and time are selected. In ethnographic studies the number of informants is not as important as the depth of information that they provide that illuminates the phenomenon under study (Lincoln & Guba, 1989). Good informants are not only those that have experienced the phenomena under study, but those who are willing and able to discuss and examine their own experience (Munhall, 2007).

The following criteria were used to select informants:

1. The key informant had to be able to speak in English
2. The key informant was either male or female, from any ethnic background, and had lived in the Willcox community for at least five years
3. The key informant must be 18 years of age or older
4. The key informant was willing and able to talk about their definitions, perceptions, utilization, or lack thereof, of local health services.
5. The key informant was able to participate in the scheduled interviews.

Exclusion criteria included those community members that were current patients of the investigator in her private primary care practice; although those patients that received care in the same clinic by another provider were allowed to participate.

Recruitment of Informants

Participants were recruited through the investigators private primary care practice, two other community clinics, the local hospital, and advertising with local radio stations with contact information for voluntary involvement. Once a key informant was identified according to the inclusion/exclusion criteria and agreed to participate, they were provided with focus group or interview information and a reminder telephone call was placed the

day prior to participation to secure and remind them of their involvement. Key informant interviews were conducted on those community members that wished to participate but were unable to comply with the arranged focus group times.

Procedures for Protection of Human Subjects

Human subject's protection was approved by the Humans Subjects Committee at the University of Arizona prior to data collection on December 4, 2008. Once permission was granted and participants were identified for both key informant interviews and focus group participation, the Subject's Consent Form was provided in writing and verbally reviewed with each participant. The written and verbal review with participants included an explanation of: the purpose of the study, selection criteria, procedures, risks and benefits, confidentiality, compensation, how to contact the researcher, and their voluntary rights to participate, including their right to withdraw from the study at anytime without consequence. After the key informants signed the consent form, they were given a copy if so desired. If the key informant was illiterate the consent form was read to them. There were no known risks to participate and information obtained was treated in an anonymous and confidential manner. Consent forms were signed prior to participation in the research study. Consent included permission for the interviews and focus groups to be tape recorded. The participants were assured that any identifying information was deleted. Pseudonyms were used and audiotapes were destroyed once transcription and analysis was complete. Each consent form was signed by the investigator. All research personnel completed the CITI human subject's protection training.

Data Collection Procedures

In order to fully assess a community's capacity and gain an understanding of their lived experiences, subjective data must be obtained that facilitates an understanding of residents' beliefs, perceptions, and values about their community's strengths and needs through key informant interviews and participant-observation in the community (Russell et al, 1996). Together these approaches provide a well-rounded view of the community that aids in community knowledge building and empowerment with the goal of improved community health.

In ethnographic study, data collection and analysis of qualitative data are done simultaneously with interviewing, recording, and analyzing is conducted until data saturation occurs (Munhall, 2007). Ethnographic research maintains three primary data collection methods: 1) participant observation, 2) interviews, and 3) field notes. Data collection for this study occurred in three parts: 1) participant observation; 2) informant interviews and/or focus group; and 3) review of field notes. Each of these data collection methods is presented and discussed in terms of how they were operationalized in this study.

Participant Observation

To acquire a systematic picture of the participants' worldviews, participant observation was used to gather data in social situations. The key component of participant observation is the investigator is present in the world of the people under study, as opposed to bringing the participants into the world of the investigator. While previous observations had been made throughout the Willcox community, by the

investigator, the activities, people, and physical aspects were revisited through a wide-angled lens. A detailed record of both objective observations and subjective feelings were maintained as the investigator alternated between insider and outsider experiences in the form of field notes. Participant observation at multiple community meetings was performed. These meetings included: Meth Task Force/Willcox Against Substance Abuse (WASA), city council, local hospital board meeting, Willcox School Board meeting, and Rotary Club. Types of participation ranged from nonparticipation to active participation (Munhall, 2007). Active participation occurred as the investigator sought to tap informants' knowledge about the health scene. For example, informal questions for public comment in community meetings included:

> What do you see as the top five health issues facing the Willcox community? and
>
> What are the top five health needs of the Willcox community?

Informal questions for those attending/involved in community meetings included:

> How is this group addressing the health issues/needs of the Willcox community? and What do you view as the top five health issues/needs of the Willcox community?

Consistent with criteria for informing participants about the study and their rights, a Subject Disclaimer Form was read during the public meeting prior to the investigator engaging the meeting leaders and attendees in discussion. Once the verbal approval was received by the investigator, the informal questions presented earlier were asked of the informants.

Focus Groups and Key Informant Interviews

Two focus groups were conducted by and investigator and community moderator. All materials for the study, including the informed consent and the interview schedule was developed in English and written at a sixth-grade reading level. Focus groups were conducted using Krueger's (1998) guidelines for moderating focus groups. Key informant interviews were conducted on those participants that were unable to attend the scheduled focus group meetings. This occurred after the focus groups were conducted. The investigator strengthened the reliability of this study by collecting data in the participants' natural and convenient setting (interviews) and in a neutral location (focus groups).

To avoid the problem of overlooking important ethnographic data, a descriptive question matrix was used for both key informant interviews and focus group dialogue. In the beginning, focus groups and interviewees were asked the same questions. Further questioning was dependent on the depth of responses and group dynamics. Group synergy was obtained. Consents were verbally reviewed and signed before questions were asked. A focus group questionnaire was distributed to gather basic information and to substantiate representativeness. Questions included: age, gender, ethnicity, number of years lived in this rural community, and did not contain any identifying information. To view the interview guide, please see Appendix C. Participants were thanked for participating, reminded of the informed consent and the voluntary nature of the study, and their right to withdraw participation at any time.

Interviews and focus groups were audio taped and privacy was afforded all informants. The audio taped interviews and focus groups, about 90 minutes in length, were transcribed verbatim by a contracted transcriptionist. Transcribed information was checked for accuracy, when the transcription was considered valid, data analysis began. Additional or follow-up questions were addressed in key informant interviews and during member checks. No obstacles to accessing participants were encountered.

Although ecological validity is usually high in ethnographic research, threats should be recognized (Mackenzie, 1994). Three key informant interviews were conducted and continued until saturation of categories occurred through redundancy.

Secondary Data Analysis

Community data was also utilized in the forms of: Community history documents and US Census Bureau data, Centers for Disease Control and Prevention National Health Interview data, and Department of Health and Human Services Vital Statistics at the country, state, county, and community levels. This data was used only for the purpose of describing the Willcox community and comparing demographic trends to county, state, and national data. Data sets from these institutions are considered both reliable and valid for this purpose.

Measurement

This community assessment with ethnographic underpinnings can be viewed as a naturalistic paradigm. Naturalistic paradigms use the human subject as the primary data source for the study with the researcher as the primary instrument. The human instrument uses procedures that extend normal human activities: interviewing, observing,

scrutinizing available documents and records, evaluating nonverbal cues, interpreting unobtrusive measures, and scrutinizing field notes (Lincoln & Guba, 1985).

Although field notes were kept for each meeting, the primary data collection technique was audio recorded interviews. From these audio recorded interviews, transcription was performed in which spoken language became something different – text. The transcribed interviews were crucial to analysis since replication is not possible and reflection upon an event can be said to change the context of the event.

Audio recorded interviews and the keeping of field notes is consistent with the naturalistic paradigm. One dimension of data recording is "fidelity" of the ability of the researcher later to reproduce the data exactly as they become evident to him or her in the field. Although audio recordings have the greatest fidelity, field notes provide an added dimension to the data with the recording of observations about the participant's behaviors and interactions while allowing the researcher to record her own thoughts, descriptions, and interactions throughout the study. These notes also constitute text that is open for scrutiny and analysis (Lincoln & Guba, 1985).

Process of Analysis

Data analysis began with the data collection process and continue throughout the study. While the methods of data collection used in ethnography are common in their designs, ethnographic analysis is not. Data analysis is continual and ongoing, and as fieldwork progresses informants' responses are compared through repeated interviews (Lincoln & Guba, 1989). An ethnography is an inductive process and the analysis is iterative, going back and forth amongst the data sources until a coherent cultural profile

or picture emerges. Data analysis involves the following steps: 1) reading the transcribed interviews, focus group meetings, and field notes; and 2) inductive generation of domains, categories, and cultural themes.

Data Analysis

With qualitative research methods, theory is not derived, borrowed, or modified from other fields but rather emerges from observation of and participation in an actual phenomenon. Norris (1982) believes that the phenomena that nurses have the social mandate to manage, concerns human health, illness, and comfort. Newman (2005) identifies additional patient-nursing phenomena, such as reciprocities, patterns, configuration, rhythms, and composition, and emphasizes context dependency, recognizing the simultaneity of our human-environmental processes. It is the aim of qualitative research to describe and explain the pattern of relationships which are traditionally done with a set of conceptually specified analytic categories. Categories must be generated deductively or inductively with the challenge of maintaining the language in which the informants spoke to generate the categories - not imposing categories from outside the culture (Agar, 1996).

Thematic analysis.

Two basic approaches to data analysis were utilized: thematic analysis and thick description. Thematic analysis involves repetitive reading and critical reflection of field notes, transcribed interviews and focus group dialogue, documents, diaries, and appointment records by the investigator. The first step of this process was to identify themes and phrases which describe the meaning of health for each participant. Attempts

were made to identify well-defined descriptions from the participant's viewpoint. After each text had been coded, the data sets were examined to discover patterns in the data that included similarities, variations, or absence of patterns. Once these were identified, they were grouped according to similarities. The categories were then grouped into themes which describe what health meant within the sample group. The identification of themes is a critical part of data analysis. DeSantis & Ugarriza (2000) provide a definition of the theme as an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole.

The process of theme generation considers all data that has been collected, including both observation of participants' behavior and interview data (Leininger, 1985). For this study, the following steps were taken in data analysis: 1) patterns identified from raw data and listed; 2) patterns were combined into themes or larger meaningful units of relatedness; and 3) themes were synthesized to create a broad, comprehensive, holistic view of the data in the form of categories. Throughout this process, thick description was used as discussed below. One academic advisor and one methods expert reviewed the statements, categories, and themes for congruence of findings and to establish reliability.

Thick description.

The second approach to data analysis, thick description, was used as described by Geertz (1973). This approach involves looking beyond the more evident patterns and to identify for outsiders underlying meaning as patterned, structured, and understood by those who share a common language and experience. A thick description involves

providing a data base sufficiently broad to allow for transferability of findings. This means that enough description of the phenomenon is given so that someone examining the findings has enough information for application and/or comparisons of similarity within another setting (Lincoln & Guba, 1985). Thick description goes beyond recording what a person is doing and surface appearance. It presents detail, context, emotion, and describes social relationships that join people together. Most importantly, it inserts history into experience (Denzin & Lincoln, 2000).

Evaluation Criteria

Evaluation of Qualitative Data

Lincoln and Guba's (1985) guidelines for rigor in qualitative studies were utilized to assure accuracy of findings along with Geertz's (1974) work on thick description. Criteria for establishing rigor in qualitative studies are very different from quantitative studies. Trustworthiness is the qualitative term that corresponds to the general quantitative terms of scientific rigor. Long term professional involvement in the Willcox community provided prolonged engagement in the field. Field notes were written post-interview and after participant observations and was used to supplement transcribed data. Data was audio taped and transcriptions were reviewed by the investigator to ensure the accuracy of questions posed and the participants' replies which was useful in developing themes and categories. Saturation was determined by redundancy of answers by key informants from differing groups. Committee debriefing processes involved the screening of methods, data, categories, and themes by methodology and included the aid of a content and methodology expert.

The following criteria were used to establish trustworthiness in this qualitative inquiry: credibility, confirmability, dependability, and transferability (Lincoln & Guba, 1985). These four criteria were applied to this study and are defined and discussed below. Reflexivity of the researcher will also be discussed.

Credibility

Credibility is equivalent to internal validity in quantitative study and refers to the accuracy of interpretation of data and findings through prolonged engagement in the field (Lincoln, 1995). Credibility was established in this study through prolonged engagement in the community, member checks, and triangulation. Each of these techniques is discussed below and how they related to this work.

Prolonged engagement.

Prolonged engagement provides credibility by ensuring that enough time and involvement with the informants and their community occurs to correctly evaluate and represent findings within the cultural context (Lincoln & Guba, 1985). This study occurred over a five month period. Prior to this study, the investigator had worked as a health care provider for four years in this community, was born and raised until the age of 18 in the community, and thus had insider status. For these reasons, prolonged engagement was well-established.

Threats to credibility and the ability of the participants to speak the truth was an anticipated issue due to culture and power differentials between informants and the investigator. (Engebretson, 1994; Hess, 1996). The investigator was seen as a professional and as a provider of health care within the community; the informants could

have felt coerced into consent (Mackenzie, 1994). This threat was minimal since patients of the investigator were not allowed in the study, as set forth in the exclusion criteria. Also, as previously mentioned, the investigator had maintained a collegial relationship with the community for four years as a professional, was born and raised until the age of 18 in this community; hence, the investigator had insider status and could be viewed as a community advocate for healthcare. To ensure these power differentials had a minimal effect on data collection, this study included the participation of a local registered nurse as moderator of the focus groups. Her involvement aided in data collection through her familiarity with the culture and community context. This degree of familiarity with the community helped narrow the gaps between investigator and informants, thus minimizing the "elite bias" (Lincoln & Guba, 1985, p. 32).

Member checks.

Member checking is a process that allows the researcher to take the findings in the form of patterns, themes, and categories to be verified by key informants for accuracy (Sandelowski, 1986). The process of taking the findings back to the community was accomplished through individual meetings, provision of transcripts for review through mail correspondence, and focus group follow-up. This process ensured accuracy and solicited further insights from participants, while allowing distortions or misrepresentations to be clarified. Peer debriefing with the dissertation chair and expert methods consultant was also used to ensure data collection methods and interpretation processes were rigorous (Lincoln & Guba, 1985).

Triangulation.

Triangulation contributes to the richness and depth of understanding of the phenomena being studied. Recognizing that objective reality can never be captured, triangulation facilitates knowing about phenomena by use of multiple methods. Triangulation reflects an attempt to secure an in-depth understanding of the phenomena in question by adding rigor, breadth, complexity, richness, and depth to inquiry (Denzin & Lincoln, 2000). Theoretical triangulation was conducted through the use of multiple levels of data at the individual, group, and community levels with theoretical linkages being made with community capacity theory and rural nursing key concepts.

Confirmability

Lincoln & Guba (1985) define confirmability as the degree of investigator neutrality in interpreting the phenomena under study; or in the scientific rigor paradigm, objectivity (Lincoln, 1995). The findings should reflect the perspectives of community members, rather than the perspective of the investigator. An audit trail is the primary technique for establishing confirmability as it provides linkages between the raw data and final interpretations. The audit trail for this study included field notes, raw transcripts, and a series of investigator reflections and theoretical decisions linking and justifying the findings. The most critical component of this audit trail was the investigator's diary of reflective thoughts.

In true ethnographic methodology, the investigator is an outsider that studies a "foreign" culture to obtain the emic viewpoint and rally this viewpoint against their etic background. Due to the investigators insider status, complete enculturation had the

potential to skew data collection and analysis as the etic view does not exist (for this investigator). To address this threat, the investigator included the participation of an outsider to observe and document perceptions of focus group participation and participant observations.

Dependability

Dependability refers to the stability of the data analysis process and is similar to internal consistency and repeatability of the study. According to Lincoln & Guba (1985), credibility must be established prior to dependability; much like in quantitative studies, establishing reliability before validity is essential. The multiple and overlapping methods used in data collection represents a form of triangulation that strengthens credibility and therefore provides evidence for dependability. An audit trail was maintained to monitor decision making in the process of conducting the investigation and to verify the consistency of the analysis process. The dissertation chair periodically reviewed the methodological processes, materials were shared between committee members, and an external methods consultant was used during the progression of the study.

Transferability

Transferability is equivalent to external validity in a quantitative study (Lincoln, 1995). In order to establish transferability, the investigator must provide the context, data, and conclusions in sufficient detail to enable other investigators to estimate the applicability of the findings to another inquiry. In order to meet these requirements, it is essential sampling techniques result in participants that are able and willing to provide rich and extremely descriptions of their beliefs, culture, and experiences. To aid in this

process, transcripts of taped interviews and focus groups, field notes, and iterations in the process of analysis was maintained. Despite the investigators' attempts to maintain adequate sampling that provides rich description, providing an index of transferability is not the investigator's position. According to Lincoln & Guba (1985), the researcher is only responsible for providing the database that makes transferability judgments possible by the potential appliers of the research.

The Researcher and Reflexivity

The researcher has been a nurse practitioner in the community for the past 4 years, but was born and raised in the community until the age of 18. Many of those involved in the focus groups and key informant interviews are well known to the researcher both professionally and personally. It was an enlightening experience to be involved in this discovery process while embedded within the community from the perspective of the researcher, with objectivity derived from education, experience, and an ethical value for systematic research.

A researcher's reflexivity addresses the strain between being a researcher and becoming a member of a culture (Speziale & Carpenter, 2007); however, the researcher was not only a researcher and a participant-observer of this culture. The researcher was also a community member and local primary care provider. It is essential to address this factor in keeping with the rigor of the study. Researchers cannot isolate research participants from their environment; conversely, researchers should not isolate themselves from their own context. Unfortunately, this has the potential to impact perceptions and interpretations (Reed, 1989). The researcher's employment in the

community as a primary care provider certainly had the potential to increase credibility in conducting interviews and obtaining consents, although careful attention was paid to not use the position of power to secure interviews or participants. The fact that the researcher grew up in this community and now was employed in the community for several years allowed her to be treated as an insider and increased acceptance. There was no obvious reluctance to participate based on familiarity. Nevertheless, during focus group interviews, the use of a local moderator was used to pose questions to the participants and an outside observer was used to ensure at etic viewpoint was seen. During key informant interviews, the researcher was careful to ask for further explanations and clarifications, so that assumptions weren't made based on personal knowledge or history. Even with these precautions being taken, there is still the potential that some participants weren't completely forthright in answering many of the questions posed; although it appeared in the transcribed text that participants were extremely candid and open to discussing the issues at hand.

Evaluation of Quantitative Data

Quantitative data for this investigation derived from secondary data analysis for existing community data from historical documents, US Census Bureau data, Centers for Disease Control and Prevention National Health Interview data, and Department of Health and Human Services Vital Statistics at the country, state, county, and community levels. This data was used solely for the purpose of describing the Willcox community and comparing demographic trends to county, state, and national data. Data sets from

these institutions have well-established histories of scientific rigor and are considered the gold standard in describing populations based on a number of demographic measures.

Generalizability must be addressed with any use of quantitative data, even if it is used for the sole purpose of describing a community's demographic profile. The above sources of data have limited generalizability to populations outside the particular community under evaluation; although it is anticipated trends seen at the local level will be similar at the county, state, and national levels.

Conclusion

This chapter has outlined the research methodology used to answer the proposed research questions. A community-based intervention approach was proposed utilizing community assessment with ethnographic underpinnings, drawing from GENESIS, to evaluate a rural southeastern Arizona border community. Procedures for protection of human subjects, the research site, criteria for participant selection, and recruitment of informants were discussed. Data collection methods, processes of analysis and evaluation including issues of rigor were addressed.

CHAPTER FOUR

CONTEXT AND PARTICIPANTS

This community assessment was conducted in the rural community in southeastern Arizona during the spring of 2009. The formal data collection of two focus groups, three key informant interviews, and participant observation began December 4, 2008 with approval from the IRB. Prior to the interviews and focus groups, relationships were established and many members of the community knew of the researcher's in studying health issues, needs, perceptions, and utilization of health services.

Description of Community

Willcox is located on Interstate 10 halfway between Phoenix, Arizona and El Paso, Texas, approximately 90 miles east of Tucson. Willcox is in the northern section of the Sulpher Springs Valley which cuts through Cochise County for nearly 100 miles averaging more than 15 miles in width. Willcox was established in 1880 and incorporated in 1915. At a high elevation, 4,156 feet above sea level, on the eastern edge of the Sonoran Desert, Willcox has a mild, year-round climate. Willcox serves as the major trade and service center for agriculture and tourism within the county. Within city limits, population is 3,828 (US Census Bureau, 2007); however, this community comprises several outlying communities within the Sulpher Springs Valley. General area population is estimated at 15,000 and includes the communities of Bowie, Cochise, Dragoon, Elfrida, Pearce, San Simon, Sunsites; although all of these communities do not have reportable data to the US Census Bureau (Willcox Chamber of Commerce & Agriculture, 2007). Cochise County has an estimated population of 127,866 (US Census

Bureau, 2007). Below, 2006 Census Data estimates from these communities are represented:

Town	Population
Bowie	2,274
Cochise	Data Unavailable
Dragoon	Data Unavailable
Elfrida	5,229
Pearce	Data Unavailable
San Simon	Data Unavailable
Sunsites	Data Unavailable
Willcox	3,828
Total	11,331

Table 2: Selected Demographics of Willcox Service Area (US Census Bureau, 2007)

Historical Background of Community

Understanding the historical background of the Willcox community is essential to understanding the perceptions and beliefs of the people that reside in the community. All rural communities are experiencing changes in their economic base and where the money comes from – Willcox is no different. Of equal importance is an understanding of the healthcare climate the people have endured over the years – both positive and negative changes.

Agriculture History

Willcox began as a small cow town and was once known as the "Cattle Capital" of the nation. Cattle are still an important aspect of the economy, with the presence of a large livestock auction that still holds livestock sales weekly. Row crops such as cotton and small grains are significant as well. The diversification of agriculture has resulted in the establishment of apple orchards, pistachio and pecan groves, ostrich farms, grape

vineyards, two hydroponic tomato green houses, and several mega-farms. A well-established U-Pick-it industry provides fresh produce for all of Southern Arizona and Southwestern New Mexico. There are dozens of U-Pick farms in the Willcox area. A variety of different fruits and vegetables can be harvested, and has become a tradition for many families to travel to Willcox annually to pick their own fresh produce. Tourists, as well as traveling business people also have an important impact on the city's economy (Willcox Chamber of Commerce & Agriculture, 2007).

Healthcare History

Northern Cochise Community Hospital (NCCH) is the primary source of services within the Willcox community with being the only hospital in a 50 mile radius of the community. NCCH was organized in 1968 as a not-for-profit corporation. It is now a Critical Access Hospital providing basic medical, ambulatory, and emergency care. The hospital is governed by a district board and a corporate board that oversees the business of the entity. The district board consists of seven members: the Chief of Staff, five members elected by the residents of the hospital district, and one appointed member (Northern Cochise Health System, 2009). The following quotation is from their website,

> "Through the sacrifices of many, we have managed to make quality healthcare a reality for Willcox, Arizona. Being a part of the community has been an important goal, and with your help and loyalty we can continue to provide health services that you can depend on" (Northern Cochise Health System, 2009).

Several private practice physicians have practiced in Willcox over the years. Since the 1960's there have been an estimated 20, some of these retiring in the area with others

moving to new communities. In 1994, NCCH opened Sulpher Springs Medical Center and began hiring physicians to staff this new clinic. Two years later, Sunsites Medical Clinic was opened to serve the retirement community of Sunsites-Pearce. Today, there are four clinics that serve the Willcox area: Bushman Clinic, Sulpher Springs Medical Center, Sunsites Medical Clinic, and Walker Family Medicine. These clinics are staffed by three physicians, three nurse practitioners, and one physician's assistant. Two of these clinics are privately owned while two are owned by the local hospital and are designated Rural Health Clinics.

NCCH has grown over the years to now include a nursing home and two freestanding rural health clinics. The hospital also has visiting specialists that usually will come into the community and hold clinic one to two times per month. These specialists include: cardiology, dermatology, obstetrics/gynecology, podiatry, orthopedics, Due to the recent growth, the leadership committee of NCCH decided to add the name Northern Cochise Health System to the entity (Northern Cochise Health System, 2009).

Despite this growth, in 2007, NCCH administration with the backing of the governing board attempted to close down the nursing home. This sent shockwaves through the community emotionally and politically – possibly forever altering the course of the institution and the community's trust. On the community members' side, they saw an essential piece of the community crumbling before them; a place where their mothers and fathers live; where they saw themselves potentially living one day. This was viewed as a threat to the community and its ability to take care of the elderly. It was cited that

the nursing home was operating in the red and it was pulling the hospital down with it. The community's anger at possible closure forced the board to comprise a committee made of community members to steer possible ways to save the facility. Upon their audit, portions of tax dollars received from the county were not being used in the nursing home and it was still operating in the black. For this reason, the nursing home is still standing and operating today; although, the administrator and three board members that made the recommendation are no longer involved in the institution.

Emergency services available in Willcox include an ambulance system with full-time helicopter transport availability. Up until 2003, NCCH Emergency Department was staffed by the local providers 24 hours a day. In this year, a full-time emergency physician was employed by NCCH with the local providers covering off hours. In 2006, NCCH decided to contract emergency medical services out to EmCare, an emergency medicine physician staffing agency. Now emergency medicine physicians migrate into the community to provide care, but are not living in the community.

Significance to Study

Understanding the local context and history is essential to understanding where participants are gaining their beliefs and perceptions. It has been well-established throughout rural literature that health is viewed as one's ability to work with deep-seeded self-reliance and informal networks at play. Therefore, understanding the driving forces behind the local economy is central to understanding why people have the beliefs and perceptions they have regarding health and how they access care.

There are two processes at work in the above history that impacts how services are utilized in this community. First, the distrust that developed after the threatened closure of the nursing home has had an enormous impact on the community and how people access and use services. This distrust could take years to rebuild. Second, the use of contracted emergency physicians to come into the community has not been well received by the community. It is anticipated this is because they are outsiders – data analysis will possibly reveal this dynamic.

Community Demographics: Secondary Data Analysis

It is important to understand the demographics of the rural milieu, meaning the age and ethnicity of rural residents and the socioeconomic climate. Geographic location and isolation have been established throughout the literature and the impact they have on health. Of equal importance is the rural dwellers definition of health and healthy behaviors that are practiced within rural communities. All of these characteristics of rural populations are shaped by the populations' access to health care.

Age

As previously established, the age configuration of rural populations tends to get older as urbanization decreases (CDC, 2002; ERS, 2007). In 2006, the US had 36 million elderly persons, considered age 65 and older. This number is an increase of 3.7 percent since 2000. Metropolitan regions gained 4.1 percent more elderly between 2000 and 2004. Whereas, non-metropolitan areas saw only a 2.3 percent increase. Despite this lower population growth, non-metropolitan areas generally have a higher proportion of

elderly when compared to metropolitan areas, constituting almost 15 percent of the rural population compared to 11.7 percent in urban areas (ERS, 2007).

In comparing these national numbers to Arizona, Cochise County, and Willcox it is clearly evident that as urbanization decreases the population tends to get older. In Willcox alone, 16% of the population is greater than 65 years of age; compare this percentage to the county (14.7%), state (13.0%), and US (12.4%) values and it is clear Willcox is above the national, state, and county percentages for elderly population. Below is a statistical summary of age distribution at the local, county, state, and national levels by census year. It is important to note the 2006 data is derived from US Census Bureau Community Survey data. These surveys are not conducted on communities less than 65,000. For this reason, values for the Willcox are unavailable. Bisbee, Arizona, the county seat of Cochise county, is also lacking information for the same reason. In fact, Community Survey data is unavailable for any town within Cochise county.

Age Group by Census Year	Willcox (#/%)	Cochise County (#/%)	Arizona (#/%)	US (#/%)
Under 5 years				
2000				
2006	258/7% Data Unavailable	7,966/6.8% 9,095/7.1%	382,386/7.5% 479,145/7.85	19,175,798/6.8% 20,385,773/6.8%
18 – 65 years				
2000	2,636/70.6%	86,756/73.7%	3,763,685/73.4%	209,128,094/74.3%
2006	Data Unavailable	95,745/74.9%	4,539,463/73.6%	225,633,342/75.4%
>65 years				
2000	597/16%	17,365/14.7%	667,839/13.0%	34,991,753/12.4%
2006	Data Unavailable	20,594/16.1%	789,751/12.8%	37,191,004/12.4%

Table 3: Age Distribution at Local, County, State, and National Levels (US Census Bureau, 2000; 2007)

All of this data, both the 2000 Census numbers and the 2006 estimates provided from the Census Community Survey, is especially troubling since the nation's elderly

population is expected to double by 2050. The concentration of rural elderly is projected to increase, especially into 2011 when the first members of the baby-boom generation will be reaching age 65 (Rogers, Goldstein, & Cooley, 1993). Woods and Poole (1997), later projected, that by 2020, the non-metropolitan population would be highest in the 55 – 69 age groups. Couple these projections with an in-migration of retirees into rural communities and an out-migration of younger people, in order to find employment, and the end result is an aging rural population (ERS, 2002). It is now projected those "aging in place" alone in nonmetropolitan areas, currently at six percent in this decade, will increase by 18% in the 2010s (ERS, 2007)

In considering the high concentrations of elderly in rural areas, a challenge is presented to rural communities since the demand for social and health services increases as the population ages, when rural communities are already challenged to access baseline services. Although, currently, the vast majority of the Willcox population is between the ages of 25 and 54 (median age 36.9 years), this has huge implications for the future of the community in relation to future workforce and increasing need for health services.

Ethnicity

In Chapter One, it was discussed that rural dwellers tended to be white and native born residents (US Congress, 1990). However, the racial and ethnic makeup of rural communities is dramatically changing. Minorities now comprise 18.3 percent of the non-metropolitan population nationwide and are geographically dispersed throughout the nation (ERS, 2007). The number of Hispanics grew substantially between 1990 and 2000, by 70 percent. This is a higher percentage than any other racial or ethnic group (ERS,

2003). Contrary to popular belief, this growth is not just in the Southwest, due to its close proximity to the Mexico border. In fact, approximately half of the rural Hispanic population lives outside of the traditional Southwestern US (Whitener & McGranahan, 2003). This is also true of Willcox, Cochise county, and Arizona demographics with the reported number of Whites compared to Hispanics being drastically different. The US Census Bureau does not count illegal immigrants or even non-citizens so the values are skewed substantially. Below is the statistical breakdown of ethnicity for Willcox, Cochise County, Arizona, and the US from 2000 Census Bureau statistics and 2006 Census Bureau Community Survey data.

Ethnicity by Census Year	Willcox (#/%)	Cochise County (#/%)	Arizona (#/%)	US (Number/Percent)
White				
2000	2,798/75.0%	90,269/76.7%	3,873,611/75.5%	211,460,626/75.1%
2006	Data Unavailable	106,528/83.4%	4,741,310/76.9%	221,331,507/73.9%
Black				
2000	26/0/7%	5,321/4.5%	158,873/3.1%	34,658,190/12.3%
2006	Data Unavailable	5,442/4.3%	207,837/3.4%	37,051,483/12.4%
American Indian				
2000	60/1.6%	1,350/1.1%	255,879/5.0%	2,475,956/0.9%
2006	Data Unavailable	1,636/1.3%	277,732/4.5%	2,369,431/0.8%
Asian				
2000	31/0.8%	1,942/1.6%	92,236/1.8%	10,242,998/3.6%
2006	Data Unavailable	1,800/1.4%	144,858/2.3%	13,100,095/4.4%
Pacific Islander				
2000	2/0.1%	301/0.3%	6,733/0.1%	398,835/0.1%
2006	Data Unavailable	128/0.1%	10,960/0.2%	426,194/0.1%
Other				
2000	658/17.6%	14,193/12.1%	596,774/11.6%	15,359,073/5.5%
2006	Data Unavailable	8,779/6.9%	633,350/10.3%	19,007,129/6.3%
Hispanic/Latino				
2000	1,557/41.7%	36,134/30.7%	1,295,617/25.3%	35,305,818/12.5%
2006	Data Unavailable	40,331/31.6%	1,803,377/29.2%	44,252,278/14.8%

Table 4: Ethnic Distribution at Local, County, State, and National Levels (US Census Bureau, 2000; 2007)

It is evident in this data that the ethnic groups do not add up to 100 percent. This is attributed to many people being biracial and as an example may consider themselves both Hispanic and White.

Socioeconomic

As previously discussed, throughout the mid-20th century, farming dominated rural economies. In today's global economy, that is not the case; seven out of eight rural counties are dominated by manufacturing, services, and other employment opportunities, not related to farming. Job growth in rural farming communities is now from agribusiness, processing and marketing of agricultural goods (ERS, 2007).

Rural economies now depend heavily on three main assets to generate their economies: natural amenities for tourism and retirement; low-cost, high quality labor and land for manufacturing; and natural resources for farming, forestry, and mining (Whitener & McGranahan, 2003). This has led to a diversification of rural economies nationwide. Those rural areas, that sustain their economies with the natural amenities, attracting tourism and retirees, have benefited from growth. This has been accomplished through the immigration of retirees that help in boosting the tax base that helps sustain local businesses. However, those rural communities that rely on their natural resources for farming and mining have had declining economies due to an out-migration of younger working-age people, resulting in lower tax bases and dwindling populations (ERS, 2002). Despite the growth found in rural communities that sustain their economies through the in-migration of retirees, there is a resultant socioeconomic strain placed on these communities to provide health services for this aging population. As mentioned earlier,

the demand for social and health services increases as populations' age. This places further burden on rural communities that are already challenged to provide and access baseline services.

Despite the rural assets, rural communities continue to struggle do to a lack of well-educated and skilled workers. In today's economy, manufacturing employers are interested in rural areas that include well-educated and skills workers that accept lower wages. Rural areas that have poor public school funding, lack of post-high school education, lacking educational attainment, and high economic distress are having difficulty attracting businesses into their areas (Whitener & McGranahan, 2003).

Below are educational statistics for the US, Arizona, Cochise County, and Willcox. It is important to note in these statistics the dramatic drop in education attainment when comparing Willcox to county, state, and national levels. This decline in education attainment may be attributable to a lack of post high school education options in the county. In Cochise county there is one community college that offers post high school education with a limited number of course offerings in the Willcox community. Also, as mentioned previously, there is a lower number of jobs in rural communities that require post high school education; therefore, those that live in rural communities tend to be less educated. Those that do obtain education past high school often out migrate due to a more diverse job market.

Unprecedented economic growth during the 1990s benefited rural areas. Rural real per capita income grew from $16,506 in 1993 to $21,831 in 2000, and the percentage of rural people in poverty fell from 17.1 to 13.4 percent over that period. Welfare policy

changes (including time limits on assistance and stiffer work requirements) and the growing economy contributed to declines in food stamps, assistance to needy families, and unemployment insurance payments. But, the 2001 recession caused rural income growth to slow and poverty and assistance payments to creep back up. Despite rural growth prior to the recession, the large gap between the average rural income and the much higher average urban income remains (ERS, 2005).

Social Characteristics: Education Attainment	Willcox (#/%)	Cochise County (#/%)	Arizona (#/%)	US (#/%)
High School Graduate or higher 2000 2006	 1,390/61.0% Data Unavailable	 60,211/79.5% --/84.5%	 2,636,637/81.0% --/83.8%	 146,496,014/80.4% --/84.1%
Bachelor's degree or higher 2000 2006	 212/9.3% Data Unavailable	 14,247/18.8% --/20.4%	 766,212/23.5% --/25.5%	 44,462,605/24.4% --/27.0%

Table 5: Education Attainment at Local, County, State, and National Levels (US Census Bureau, 2000; 2007)

Rural working families also rely more heavily on benefits from assistance programs and less on family income earnings than working non-poor families (ERS, 2000; 2007). The US Census Bureau reported the national poverty level for families and individuals at 9.2 percent and 12.4%, respectively. These numbers are dramatically different at the state (9.9%, 13.9%), county (13.5%, 17.7%), and local levels (21.6%, 27.0%).

The bottom line is 69 percent of rural residents live below the poverty level, compared to 61 percent of urban residents. Rural communities have a disproportionately

higher percentage of Medicare beneficiaries and those residents under 65 are disproportionately uninsured (Arizona Rural Health Office, 2004).

Economic Characteristics	Willcox (#/%)	Cochise County (#/%)	Arizona (#/%)	US (#/%)
Families below poverty level 2000 2006	209/21.6% Data Unavailable	4,195/13.5% --/15.7%	128,318/9.9% --/10.1%	6,620,945/9.2% --/9.8%
Individuals below poverty level 2000 2006	963/27.0% Data Unavailable	19,772/17.7% --/18.1%	698,669/13.9% --/14.2%	33,899,812/12.4% --/13.3%

Table 6: Economic Characteristics at Local, County, State, and National Levels (US Census Bureau, 2000; 2007).

Definition of Health

As outlined in Chapter One, rural residents are 20 percent more likely, than urban dwellers, to consider themselves in fair or poor health (Ricketts, Johnson-Webb, & Randolph, 1999; Rogers, 2002) less likely to participate in preventative health, and have poorer health habits. Rural dwellers also tend to have higher rates of chronic disease and this is presenting itself as a significant problem in rural America. The majority of chronic diseases seen in rural areas include: heart disease, hypertension, diabetes, arthritis, and certain vision and hearing impairments (National Center for Health Statistics, 2006; Ricketts, Johnson-Webb, & Randolph, 1999; Rogers, 2002). The increased incidence of chronic disease in rural regions is attributable to rural residents' propensity to smoke, drink alcohol, be obese, and a lack of physical activity (CDC, 2002). The five most common chronic health conditions that result in mortality are outlined below at the local, county, state, and national levels.

Top 5 Causes of Death (2006)	Willcox	Cochise County	Arizona	US
Diseases of the Heart	25	399	10,362	654,092
Malignant Neoplasms	9	268	9,768	550,270
Accidents	1	78	3,156	108,694
Chronic lower respiratory diseases	--	63	2,771	123,884
Cerebrovascular Diseases	--	59	2,159	150,147

Table 7: 2006 Top 5 Causes of Death at Local, County, State, and National Levels (Arizona Vital Statistics, 2006; National Center for Health Statistics, 2006)

It is interesting to note the increased incidence of accidents (ranking third) at the state, county, and local levels while they rank fifth at the national level (National Center for Health Statistics, 2006; Arizona Vital Statistics, 2006). Also of special note are death rates resulting from accidents are 40 percent higher in rural areas (Ricketts, Johnson-Webb, & Randolph, 1999; Rogers, 2002). This substantial difference may be attributed to rural residents being less likely to wear safety belts and the majority of the workforce being manual laborers, the potential for job-related injuries is higher.

Participants

Participant observation was conducted at community meetings. These included: Willcox City Council, Willcox Meth Taskforce, Rotary Club, local hospital board meeting, and Willcox Unified School District Leadership meeting. Two focus groups were held at a local hotel conference room – as it would be viewed as a neutral location. The first focus group consisted of those that lived locally and used local health services. The second focus group consisted of those that lived locally but do not use local health services. Those that made contact with the researcher for participation, but were unable to attend the scheduled focus group meeting were asked to be involved in an individual

interview. This process yielded three key informants that were individually interviewed. Participants were selected to ensure representativeness of sample to the greater Willcox community. This sample is generally representative with +/- six percentage point differences between participant percentages and Willcox Census data percentages. In the table below, the demographic group represented for each type of participant is outlined as compared to 2000 Census data for the region. Data from the 2000 Census was used since 2006 data is incomplete for the Willcox community, as previously discussed.

	Local	Non Local	Total Focus Groups	Key Informants	Total Focus Groups & Key Informants	Willcox Census Data
Age						
18-65 years	6 / 75%	8 / 72.7%	**14 / 73.7%**	3 / 100%	**17 / 77.3%**	**2,894 / 77.6%**
Over 65 years	2 / 25%	3 / 27.3%	**5 / 26.3%**	--	**5 / 22.7%**	**597 / 16%**
Gender						
Male	2 / 25%	1 / 9.1%	**3 / 15.8%**	1 / 33.3%	**4 / 18.2%**	**1,827 / 48.9%**
Female	6 / 75%	10 / 90.9%	**16 / 82.2%**	2 / 66.7%	**18 / 81.8%**	**1,906 / 51.1%**
Ethnicity						
White	3 / 37.5%	9 / 81.8%	**12 / 63.1%**	1 / 33.3%	**13 / 59.1%**	**2,798 / 75%**
Black	--	--	**--**	--	**--**	**26 / 0.7%**
American Indian	--	--	**--**	--	**--**	**60 / 1.6%**
Hispanic/Latino	4 / 50%	2 / 18.2%	**6 / 31.6%**	2 / 66.7%	**8 / 36.4%**	**1,557 / 41.7%**
Asian	--	--	**--**	--	**--**	**31 / 0.8%**
Pacific Islander	--	--	**--**	--	**--**	**2 / 0.1%**
Other	1 / 12.5%	--	**1 / 5.3%**	--	**1 / 4.5%**	**658 / 17.6%**
Number of Years in Community						
5 - 10	1 / 12.5%	3 / 27.3%	**4 / 21.1%**	--	**4 / 18.2%**	**n/a**
11-20	2 / 25%	2 / 18.2%	**4 / 21.1%**	--	**4 / 18.2%**	**n/a**
Over 20	5 / 62.5%	6 / 54.5%	**11 / 57.8%**	3 / 100%	**14 / 63.6%**	**n/a**

Table 8: Demographics of Focus Group Participants and Key Informants Compared to US Census Bureau Data (US Census Bureau, 2000)

Participant Summaries

Pseudonyms were assigned to each of the key informants to protect their identity, they are described below. Each interview addressed the same questions as the focus groups with questions pertaining to the GENESIS constructs of culture, community, and health services.

Key Informant 1

Tiffany is in her early thirties, white, married, mother of three boys and has worked as a pharmacy technician for 15 years. She has lived in the Willcox area all her life – 31 years. She uses local services for her children's health needs but she goes out of town for her own medical care. She cites going out of town for specialty care that includes a gynecologist.

Key Informant 2

Drake is in his early thirties, Hispanic, married, father of three children, and is currently a sergeant for the Department of Corrections. He has lived in the Willcox area most of his life, except for moving away for two years in his early adulthood, for a total of 30 years in the region. He uses local services primarily but has recently been required to go out of town for care due to specialty needs –orthopedic consultation.

Key Informant 3

Wendy is in her early forties, Hispanic, unmarried, and mother of a recently deceased (20 year old) daughter that had cerebral palsy. She has lived in the Willcox community for 30 years. She has worked in several physician offices within the

community over the years and now works at the local hospital as a radiology clerk. She currently uses a local physician for her health care needs.

Focus Group 1: Local Users of Health Services

This group consisted of those that live locally and use local health services. Interviews were conducted at a local hotel conference room and participants signed consents. Ten participants were signed up the day prior to the meeting and eight appeared the day of the group and participated. The majority of the group was between the ages of 18-65 years, female, Hispanic, and lived in the area for more than 20 years.

Focus Group 2: Local Nonusers of Health Services

This group consisted of those that live locally and do not primarily use local health services. Interviews were conducted at a local hotel conference room and participants signed consents. Eleven participants were signed up the day prior to the meeting and all eleven appeared the day of the group and participated. The majority of the group was between the ages of 18-65 years, female, White, and lived in the area for more than 20 years.

Conclusion

The context of the study was as important to understand as the data obtained in interviews, focus groups, and from participant observation. The data must be considered in relation to the context. This chapter has described the geographical setting in relation to state, borders, the community, and recent significant events. The researcher's perspective is described along with measures taken to ensure an etic viewpoint was obtained. Background and demographics are described for the informants and focus

group participants. It is essential for context to be taken into consideration as data has the ability to take on a whole new meaning when contextual factors are evaluated.

CHAPTER FIVE

THE MEANING OF HEALTH IN A RURAL SOUTHEASTERN ARIZONA BORDER COMMUNITY

In this chapter, the meaning of health in a rural southeastern Arizona border community is presented through synthesis of the significant statements and categories as found within the transcribed interviews. The data presented describing health under the GENESIS constructs of culture, community, and health services clustered into six main themes. In the construct of culture, the theme of functionality emerged. The construct of community emerged as a two-fold theme – individual responsibility and collective responsibility. The individual responsibility is a personal responsibility for self care and ensuring personal health. Collective responsibility emerged as community health being everyone's responsibility. The construction of health services revealed the themes of trustworthiness, practicality, and perceived quality. Access to services is dependent on what is trustworthy, what is practical and perceived quality.

Theme One: Functionality

In the construct of culture, functionality emerged as a theme. According to the Merriam-Webster dictionary (2009), "functionality" is defined as "the quality or state of being functional". "Functional" means, "used to contribute to the development or maintenance of a larger whole" and "performing or able to perform a regular function". Throughout the data, health was defined by functional status, but not necessarily a particular degree of functionality. Several participants in focus group two discussed the various forms of functionality that equates with health. One participant shared,

> "The physical part that is to be able to do what you want to do, if you want to hike, to be able to hike, maybe not as fast as some of the others, but you can do that. The mental part, mental health to continue learning I think is very, very important."

Another stated,"I think it is being ambulatory, how much ambulatory as she says depends on what your choice is, and be able to do your own ADL's, take care of yourself."

As is evident throughout rural literature, health is defined by one's ability to go to work. If you are able to get up and go to work in the morning – that is health. If you are unable to work – you are not considered healthy (Bushy, 2000). Equating health with ability to work was evident in the data. A respondent in focus group one states,

> "How do we define health? Well, you can have poor health but you can still have good health, so maybe defining health is surviving, I guess and being able to get up in the morning. You try but the whole idea is to try to have good health, that is what I find, think positive, I can go to work."

Another participant in the same group shared,

> "I'm a workaholic, and like I said earlier, I don't think about the negatives of health. I probably don't eat right, I probably don't do anything right, but I don't have time for vices. I work and I eat and I sleep and luckily enough the good Lord has kept me healthy all these years."

Two key informants revealed the importance of being functional as it relates to taking care of their families. Wendy stated,

> "If you are in good health, you feel good, you have the energy to do things, you can take care of your family. You can go be active and do things and maintain that good health opposed to when you don't feel good and you're sick and you are concentrated on that, you don't have energy."

Drake shared,

> "Being able to go out and play with your kids and exer…, well by the looks of it, I don't exercise, but, like getting out, being able to go out and have fun and run and play with your kids, being able to go do things with your family and stuff, not like if someone says, hey let's go do something, you are like, nah, I can't, I can't do that, you know."

Another component of functionality stems from self-determination. Across the data, several participants cite the power of positive thinking and avoiding negative behaviors, thinking, and people. Self-determination that contributes to a healthy lifestyle was posed as a mind and body connection that can only be determined by one's actions and outlook. One focus group respondent stated,

> "Okay, I define health as spiritually and physically feeling good about yourself. Of course, when you get a certain age, like 29+, there are things you can't do that you used to do, but you accept this and you're glad that you just have arthritis in part of your body, not all of it. I think health has a lot to do with how you think, and what you want out of life. If you want to sit and be a couch potato and watch TV, you're going to have that kind of health. But if you want to go for walks and

> enjoy nature and see the sun come up and see the sun go down, then you have that kind of health. So, I think health has a lot to do with your mental attitude."

She later added,

> "Well basically I'm too busy to get sick. I live too far out to have somebody take care of me, and too broke to run to the doctor's office. Basically, mentally, physically I'll think positive about being healthy. That's it."

It is evident from this data that health is determined by functionality and relies on the interplay between mental, physical, and spiritual well-being. Functionality is measured by one's ability to work, take care of their family, and self-determination. When any one of these measures is found lacking, health also declines.

Theme Two: Responsibility

The construct of community emerged as a two-fold theme: 1) individual responsibility and 2) collective responsibility. The individual responsibility is a personal responsibility for self care and ensuring personal health. Collective responsibility emerged as community health being everyone's responsibility. These are discussed below.

Individual Responsibility

Throughout the data, it was seen that community health starts at the individual level. Health relies on the responsibility of individuals to provide personal care that enhances health at the community level. One focus group member described it as,

> "As a community, it is all about the hand washing and the hygiene and the simple things you do at home to help take care of your community, yourself. I mean,

> your community is your home first and then the outlying community is your neighborhood, and then the bigger community is the town. You've got to start with the smaller community."

Hygiene was mentioned again, more specifically in the school setting, several participants shared,

> "I think as a parent, we have kids in school, I think it is a community responsibility because if someone sends their kids to school with some disease, and then don't say anything, it's going to spread like wild fire."
>
> "So I think as a community it is the parent's responsibility to say, hey, my kids sick, I need to keep him home, and try to keep the school community safe. Vaccinations are important, too."

Individual responsibility was also spoke about more generally:

> "I think that the more informed we are, the better we're off. The more we read, you know the more you talk to your caregiver and we all have a responsibility in that, I think, living in a community."
>
> "Well I think of the community, the community as we, as the people, it is our responsibility to take care of our own health."

Another participant summed up her feelings on personal responsibility to health in relation to her spouse that has allergies,

> "You know, you got to use common sense, you can only use common sense to the best of you ability when you are fully informed of the environment. But the ultimate thing falls on you, if my husband doesn't improve, we're in the dust

bowl, we're going to have to move, whose responsibility is that? Ours? We didn't know it was a dust bowl when we moved here, now we do. And if it doesn't make an improvement, then it is our responsibility to do what is best for us."

Collective Responsibility

Throughout the data, a collective responsibility also exists for ensuring community health. During participant observations it was cited as a community issue that requires community involvement. This emerged as a civic-mindedness that starts from childhood on into adulthood. One participant stated,

"A lot of people would say, when you say what is the community's responsibility, a lot of kids coming up, and I saw this true even from 1977 on, student's attitude that that is not my responsibility, that is not my job. Unfortunately, the schools can just teach a child so much, parents have to step up and teach their children what community responsibility is, or get out and let the next generation try to do something about it. When it comes time for taxes, it is very hard to educate even a small community anymore when you have dollars being the problem, to say we need to support the community hospital, or we need to support the public school system, a lot of people will say, you know, we'll I'm retired and I'm not paying nothing for taxes, I'm going to vote this down, I'm going to vote that down. For some reason, it is very hard to get a community, even in a small town to see the responsibilities toward that community, to make it responsible for everybody in that community including that person that is saying, 'I'm not going to vote for this

> because of that'. So I don't really know how, it is the community responsibility, but I don't know how you continue to get children who stay in this community to be educated to see the responsibilities of paying taxes so that it is a successful community, it has hospitals, it has doctors. A perfect example is Sunsites. It is a retirement community and for the longest time, nobody cared about anybody down there, they just retired down there and said, the rest of the world leave me alone, this was in the 60's and 70's. Then all of the sudden after certain groups started getting in there, they realized we can't survive here without some kind of medical assistance, because we can't get to Willcox. So from that point, then they begin to bring in the things that needed to be done, but for the longest time, they didn't have any support because they were retirees and they said, we don't need to be paying that kind of money for that, until they were one of them."

This civic-mindedness extended into volunteerism,

> "This is the frustrating part, you've got places like the Food Bank and the Food Pantry that have an abundance but then they just put a limit on. We have all this food, but you can't have it because you have food stamps. You know the reason we have people on food stamps is because they need the help. Then the government says, oh but you get food stamps already, $14 a month, wooo, let's go out and buy a gallon of milk, you know. That is the sad part. If they would take some of that ability that they have at the Food Pantry and the Food Bank and put it to the Community Center for the seniors to come to, you would find that your seniors will come and eat on a more regular basis and get the vitamins and

nutrients that they need, the social skills that they desire and crave and you would find that their health would improve. You'll find that they have games and activities and stuff to keep their minds stimulated and their body active for what they can, you'll find that they become more healthy. If it was something that even the high schooler's or me, I'm a homemaker, I'm at home. I have a grandchild that I am raising. But would that limit me to go and help cook for them, no it wouldn't, I can throw her in the playpen and bring her and I'm not sure, sometimes a lot of older people think, oh what a cute baby, and a baby there sometimes has a tendency to make an older person feel better because they will dote on them a little bit, especially if they are a well behaved baby……with the health, we've got the Community Center, we've got the facilities, it is just the funding we don't have. I think if that was there, the seniors would show up more, and you would get people of my age or L5's age or L8's age that would come and be willing to volunteer an hour or two hours, or a day or half a day, or whatever to make it more function able. Not only would the seniors benefit, but I would benefit, L8 would benefit, L5 would benefit because we are putting ourselves in a position where we are being active, we are helping, we are taking care, we are being the care provider and we are cutting out a lot of the work load for Amanda and Dr. Dawn and Mick and the other physicians in this community that could be taken care of by community involvement, that the physician's here could take care of the more pressing needs like the leukemia, the cancer, the really bad colds, the heavy duty sicknesses. I think a lot of the reason why seniors come to the

> doctors, and please tell me if I'm wrong, is just to see another human being and have the human touch. I think that is sometimes why they come because they feel lonely and they need somebody to reach out and say you know what, it is okay. You are going to be okay. I think that is what it is. If we had something like that with the funding, you would find your seniors are going to do better, they are going to be more healthy. The people of my age group would be more healthy and active and happy and the health needs would be met on a more regular basis. Then the doctors could take that time to come in and say, hey, this day on this month we are going to have BP checks or we are going to have the sugar screens, or we're going to have the vision truck come, or we are going to have this here."

In regards to community leaders, respondents across all levels of data cited the need for community leaders to increase awareness of available services, potential infectious and environmental hazards. One participant indicates,

> "I think the city fathers, should we call them, have a responsibility to advise the community if there is a problem. The aquifer is full of whatever, is contaminated the wells. The crop spraying because that is an aerial thing and the wind blows it and it can affect everybody. Meth, so on and so forth."

Another cites,

> "It is their responsibility to educate us on things that are going on around us, say Valley Fever, which is an incredible increase right now as we have more and more construction. Things like flu season, yeah, it is upon us, make sure you are

> getting your shots, and making sure people know where to go and making sure people understand what is going on."

One participant stated:

> "A lot of people are not aware that there are services that can go to for help and that sometimes may be a negative situation because they don't know that could get help. If they were aware, if information was distributed, it may help people say okay, maybe you could contact this person, she'll help me with my social security check or my medical, and I know we have limited monies, but maybe we can refer them somewhere else"

Despite these examples, participant observations revealed community groups primary role in health promotion is increasing awareness of services and potential threats to health, including infectious diseases and drug abuse through community education. In response to whether education is occurring and being used appropriately, key informant Wendy stated,

> "It is being put out there, it is just the community has to respond to it. I think they are, little by little, they are responding, but a lot of them aren't."

This shows an apparent disconnect between community members and leaders. Perhaps an area for future investigation.

Theme Three: Trustworthiness, Practicality, Perceived Quality

Four concepts emerged as reasons people either out migrate or stay in town for health care. These include: loyalty to provider, low cost, specialty care needs, and technology that is used correctly and quickly. For these defined reasons, the construct of

health services revealed the themes of trustworthiness, practicality, and perceived quality. Access to and use of services is dependent on what is deemed trustworthy (loyalty to provider and specialty care needs), what is practical (low cost), and perceived quality of care (technology).

Trustworthiness

Merriam-Webster's dictionary (2009) defines "trustworthy" as "worthy of confidence". Throughout the data, confidence in health care provider and services was essential to use of those services. Many of those involved in the local nonuser of health services focus group identified with trustworthiness and why they choose to receive health care out of town. In response to choosing a provider, one mother reported,

> "I know I had my then 3 year old fell into a fire on the top of the Grahams. We get to the bottom saying; well do we go to Willcox or Safford. We chose Safford over Willcox because there is more there. You know, you've got a better chance of having somebody that understands burns than if I came here."

An older woman reported,

> "My doctor walks on water, so I won't leave her for any reason until she dies or retires, and then I will look for someone in town, but she saved my life, there is no way I'm not going to go to her."

She also added,

> "I was misdiagnosed really bad, misdiagnosed from a doctor, a specialist in Sierra Vista, and I almost died but I got a second opinion from a doctor in Tucson and she referred me to my other doctor because I didn't have a doctor, we have lived

everywhere, we never lived anywhere where there was a doctor before we came here. So I got her, those two, and like I said, the first one retired, the second one is doing everything now, and I have another specialist now that was referred by her. But honestly I'm not going to get anybody in trouble or anything, but it is a gastro doctor that I go to there and so I have to have a colonoscopy every 2 years or something, and I wanted to do it here, and I'm not naming names or anything, but my doctor said, she can't get them to cooperate with her and get the tests back and stuff, so she asked me to go to one that she could work with. So that is a problem."

One mother in a focus group discussed the importance of confidence in her child's pediatrician,

"My son actually, he was born without an esophagus, so he would have starved to death. I knew there were problems, we went to Tucson immediately and we had our pediatrician and everything there, I've always gone to Tucson. My other son is healthy as a horse, but we just take them up there for the yearly checkups and stuff. At the very beginning when they were younger, we lived out of town and it always worried me because my oldest one, he had a lot of complications on and off, like eating issues, he had to have pre-digested food for him. You know, we had to feed him in a tube through his stomach and all that stuff, so it was really hard for me to live out so far and drive to Tucson, worrying that there was going to be some bad thing happening, infected areas around where his tube was and stuff. Anyways, over time I have grown more confident in our doctors and staff

> here because, well first there were four that I have with the people that we deal with, they understand where I'm at with him and know if there is a situation that is a little bit not out of their league, but you know, needing more of a specialist view, I know that they would tell me what I need to do, send him whenever, or I know I could call my pediatrician and say, hey, this is going on with him, because his throat still never does work correctly, or his digestive tract is completely different."

She later discussed,

> "Mine is pediatric wise, I mean I go like to a podiatrist out of town and myself, if I have a cold or little things, I'll go here. But for my kids it is because of all of Tristan's issues that he had. But the other thing he'll go in and have swallow studies because there are ongoing little things with him, and I know that she'll send me right down to this lab and before I get back to her, she's already got the results back instead of waiting for a week or ten days the results will be in. That just makes it a little easier, you getting immediate response on what is going on. He's got 2 volumes, so the history is right there, and loyalty, many different reasons."

Trustworthiness is measured in the Willcox community by community engagement. It was seen throughout all levels of data, the importance of the medical provider being members of the community, being visible in the community, and treating their patients as people, not numbers. These qualities were repeatedly mentioned as

assets to the community and the degree to which a healthcare provider is trusted is dependent on these factors. One participant explained,

> "Living in this community, in a rural community, you can run into people like Amanda, or Dr. Dawn or Mick or Dr. Bushman, any one of the doctors in this community, and they can almost tell you, you don't look good, why don't you make an appointment and come in and see me. It is nice to be able to feel confident that you can see these professionals out doing normal people things, you know. People put doctors and practitioners above; you know they put them on a pedestal. In Willcox, everybody is pretty much an equal and it is nice to be able to see them and say, hey, I'm not feeling good; I'm coming in to see you. They are like, okay or if they are engrained in your personal, private circle. I had the experience a couple of summers ago working with the Little League and Mick was out there with the team, and somebody just started not feeling good, and Mick said, hold on and he went and took care of it. It is nice to see that there are people like that, that really want to come to our little community and give us some medical care. That is a big factor of being here. It is more of a personal touch, and like I said, you are not a number, you are not just a dollar sign to them, you are not an insurance claim, you are personal."

Key informant Wendy explained,

> "There is still the familyness and everybody knowing everybody, you knowing your doctors, you knowing your doctors know your family, you know, from generation to generation, so I think that is a positive."

She goes on to state,

> "I think it is a little bit more comforting that you do know them and you do see them and you do see that they are human like you are, and you know that they are in the community, too. But I think like there are doctors here that you can see, it is on a friendly basis, it is not like they are a mechanical robot, you know, just trying to make the money for the office. Really, getting down and just sitting with you and listening, I think that is a positive."

The mother cited,

> "Over the years I've been able to feel more confident in, you know you kind of have the feeling, oh Tucson, has it all, the best doctors and all that, but you tend when you have that personal connection with your doctors, then you feel confident that you can talk to them about it and that they are easier to get a hold of, I think it's better over the years, it's gotten better over time in my own eyes."

Key informant, Tiffany, offered this advice to local providers,

> "Stay involved in the community. Know the people that you are taking care of, because that will help you better take care of them. If you get out in the community and you are part of the community, then you know what the community is about and then you understand the people better and you know how to help them."

It is evident, by these citations, that community engagement is central to gaining trustworthiness in this community. This is especially evident in the discussion of perceptions of care provided. The local nonusers of health services focus groups

immediately went to a discussion of the emergency department physicians and their perceived inadequacies. Examples of mistreated cases of nurse maid's elbow and missed cardiac arrhythmias are too numerous to outline here. The central flavor of these perceptions concluded to one central idea – lack of community engagement. Examples from focus group dialogue include:

> "They try to move you out, because he is frustrated because he's got to get home wherever he lives, the doctor that has come in to stay, and he has no real tie to the community."
>
> "They have no ownership of the community when they come like that."

Key informant, Tiffany sums it up,

> "I think the personal physicians, I think the ones who are from here and the ones who have an investment into the community care more and I think it is obvious. I think you can tell, and I think you can tell the ones who are just coming in to do the service and then go back to where they are from, they don't have anything vested in."

Practicality

It has previously been established that the more rural your community is, the poorer you tend to be and you are less likely to have health insurance. This is becoming even more difficult with the turbulent nature of the national economic climate. These troubling experiences emerged in focus group dialogue,

> "I think we just heard this on the news a couple of weeks ago, people are to the point that they can't afford to think about dealing with a medical issue. So if you

> live in a rural community, as she said, she has to go so far away. If you are seriously sick, you will have a tendency to put it off, one because you can't afford to."

Another added,

> "It is just whether it is used by everybody or again our society right now is in a money crunch, people just deciding I'm not going to the doctor because I don't have $25 for a co-pay. Or I'm not going to the doctor because I don't have a ride. So we have it, I don't know that we can make it more accessible than is already is, it is just that is what our community has to continue to do, is make these accessible."

During the course of this study, it was determined that people go out of town for health services for a variety of practical reasons. These include cost of care and specialty care needs. Cost of care issues are centered on lack of insurance or having limitations on which providers the patient can see if they are to use their insurance plan. Many of those with insurance were required to travel out of town, for instance one man had veteran's benefits and thus had to go to a veterans' clinic or hospital for care. Those without insurance are forced to delay care or to migrate to Mexico for healthcare. One participant revealed,

> "I volunteer at the Springs Student Center and a lot of those kids talk about getting medical care in Mexico, going to Agua Prieta, doctors, surgeries and everything else because they can't afford the medical here."

Another participant offered,

> "Right now I'm limited because of other issues, but I used to go to AP [Agua Prieta] to the dentist because it was cheaper, I could afford it. It was cheaper for me to go into Douglas and into AP because I could go there and get the medical treatment from the dentist who was, believe it or not, trained here in the U.S. at U of A, and they are more financially accessible to go to their than it is for me to go to the dentist in Sierra Vista or Safford or Tucson or even here in Willcox."

One participant shared having to drive 90 miles to a community health center because they offer sliding scale fees,

> "The main reason I don't go here, I have the confidence, I know people that do go to the doctors here, and to me, it is everybody's own opinion, whether they like the person or not. But mine was because I couldn't afford them here, and I got on the sliding scale down there [Chiricahua Community Health Center]. So I mean, you have to do what you can survive with."

It is also common practice for those living near the border to travel to Mexico for medications their US providers have prescribed for them. One woman shared,

> "Mine is financial reasons that I qualify for. But I get my prescription of acid reflux in Mexico, if I need any medicine, I go there. (It is going to be rougher now, you are going to have to have a passport -- laughter and interaction.) I've already got it, it saves me money."

Cost of care is not the only issue surrounding the need to go elsewhere. It also has to deal with the money it takes to travel out of town for care. One participant cites,

> "I think the only way that most of us like L1 is saying to combat that negative aspect of the medical health care in a rural community is that for me, if I know that I have to go to a specialist, and like L5 says, I put it off until either a) I have no choice and have to go, or I try to put it off until I know that somebody else is going. Because it is the cost, it is more of the cost than the inconvenience, I think, for a lot of us. How to get there…."

Perceived Quality

As previously established, the IOM (2004) generalizes: the smaller, poorer, and more isolated a rural community is, the more difficult it is to ensure availability of high-quality health services. However, the data revealed that quality of care is measurable in differing ways. As was evident in the above section on trustworthiness, many of the respondents felt they were receiving good care locally because of how their provider treats them as a person and not a number. This was also a function of community engagement and being visible within the community, as examples are cited above. When multiple key informants were asked what they look for in a provider, the following characteristics were described:

Wendy described,

> "Somebody who just doesn't go in and say okay, this is it, this is it, okay I'm giving you this and that's it. I think somebody who is going to sit there and listen to you that is important."

Tiffany shared,

> "Basically somebody who, as far as in a physician or a doctor, I would seek somebody who is knowledgeable, who listens, somebody who knows their book stuff but also listens to what the patient has to say, and doesn't just go off the book. Somebody who has somewhat of a personal experience some time in something so they know how it feels to be there, or they have experienced it so they have a lot more, I think that way there is a lot more understanding in something, over just reading the book and going by the textbook answer because people are human and a text book answer does not fit every person."

Overall, all participants were complimentary of local providers that provide primary care services and this could be deemed as perceived high quality care. It is important to note, however, that the researcher was present during both focus groups and all individual interviews and the researcher was known to be one of the local providers by all participants. Therefore, respondents may have not felt comfortable sharing their true perceptions of local providers.

Conversely, participants were more than willing to share why they went out of town for care. One father had to go out of town to get his child diagnosed with nursemaid's elbow.

> "One time I had, Cory, I took him to the hospital down here. You know what happened, I was carrying him up the stairs, he was a little baby, and he was barely walking at the time. He was holding my hand and he slipped and I kind of held on to him from falling. Well, it pulled his, I think they called it nursemaid's elbow was what he had. But we took him to the ER and the doctor here said, 'Ah, he's

> fine, there is nothing wrong with him'. Well he cried all night long in pain but there was nothing wrong with him. So we winded up taking him out of town the next day and the doctors out of town, oh, right when they saw the things, they knew exactly what it was, put it back in and then he was good within.., you know….Sometimes I feel we get, you know, we don't get some of the best things because it is a rural area and they don't want to come over here.

This citation is congruent with rural literature on quality of health services – as rurality increases, quality of care is perceived as decreasing. A mother reported,

> "For pediatricians for the kids, I go to Sierra Vista, I don't know, they are good doctors, they have seen more kids, so they know more."

Another mother cited something similar,

> "Because it is a small town, maybe the patients wouldn't face the same problems that a big city might. You know, it is still that family practice type setting where they may be only responsible for dealing with the colds, or the headaches or whatever. But when the major problems come, they don't necessarily know how to deal with it."

Technology came up multiple times in regards to confidence in local services and quality of care. For the most part, more technology was equated with higher quality care. This was discussed in ease of data transfer and availability to the provider of care. Two members of the local nonuser's focus group discussed this.

> "One thing I think that is very important with where I'm going now, you were talking about the volumes, the continuity of care and the fact that the information

> is electronic and therefore should I have to go to a specialist or I'm in an accident in Tucson, they can just zip that right on over, that to me being up to date is worth everything."
>
> "He'll go in and have swallow studies because there are ongoing little things with him, and I know that she'll send me right down to this lab and before I get back to her, she's already got the results back instead of waiting for a week or 10 days the results will be in. That just makes it a little easier, you getting immediate response on what is going on."

Despite more technology equating to higher quality care, the following citation illustrates how the operator of the technology must be knowledgeable as well.

> "I had some problems here, went to the local doctor who ordered an MRI, couldn't find anything on the MRI, the pain didn't go away. I was referred by this same doctor to a specialist in Tucson and the doctor up there did an X-ray thing and he looked at it, and he said, if they had decent equipment down there they would have found it right away. I don't know how many times myself and other people I've talked to have said, they can't read the X-rays that are taken down here, they are not clear, and so they have to redo them up there. I don't think (I've heard that, too). I don't think it is because the doctors up there are looking for more money, I don't really thing that is the problem. I really think when they put the two, the one that was taken here and the one they took, up on the light, even I can see the difference, (absolutely) so they don't have the equipment here that a big hospital has, therefore it is not the new up to date stuff. (Not modern).

> (Or people that can run that equipment) That is the other thing, too, you are supposed to have something, and you call in, oh my we are supposed to have this, and the doctor is not there or the tech or whatever to run that equipment, or they have a big expensive thing and no one has been able to run it, it is like, oh my, what to do you. It doesn't instill a lot of confidence."

Conclusion

From participant observation through interviews and focus groups, information was obtained that revealed the meaning of health in a rural southeastern Arizona border community. This was presented through synthesis of the significant statements and categories as found within the transcribed interviews and field notes. The data presented described health under the GENESIS constructs of culture, community, and health services clustered into six main themes. In the construct of culture, the theme of functionality emerged. The construct of community emerged as a two-fold theme – individual responsibility and collective responsibility. The individual responsibility is a personal responsibility for self care and ensuring personal health. Collective responsibility emerged as community health being everyone's responsibility. The construction of health services revealed the themes of trustworthiness, practicality, and perceived quality. Access to services is dependent on what is trustworthy, what is practical and perceived quality.

Interactions were rich and genuine and told the lived experience of those living in the Willcox community. By the end of the focus groups, key informant interviews, and participant observations, most of the information was repeating what had already been

recorded and data were consistent with the identified themes. Once the findings were coded, it was necessary to determine what these findings meant, the significance of the results, and what to do with this information.

CHAPTER SIX

DISCUSSION

This chapter will begin with an interpretation of the findings relative to the theoretical framework community capacity theory. Integration of the findings with current rural nursing key concepts will be reviewed. Discussion focuses on the meaningfulness of this information in meeting the aims of the study. The strengths and limitations of the study will be followed by implications for nursing practice and future research.

Interpretation of Findings

The data described health under the GENESIS constructs of culture, community, and health services clustered into six main themes. In the construct of culture, the theme of functionality emerged. The construct of community emerged as a two-fold theme – individual responsibility and collective responsibility. The individual responsibility is a personal responsibility for self care and ensuring personal health. Collective responsibility emerged as community health being everyone's responsibility. The construction of health services revealed the themes of trustworthiness, practicality, and perceived quality. Access to services is dependent on what is trustworthy, what is practical and perceived quality. The interpretation of findings are organized according to the GENESIS constructs, associated themes, and the conceptual framework of community capacity theory.

The conceptual framework blended GENESIS constructs and community capacity theory to provide a basis for community assessment in a rural southeastern Arizona

border community. As outlined in Chapter Two, community capacity focuses on the valuable attributes of both individuals and the social structures that exist in communities. These attributes entail a set of dynamic community traits, resources, and associational patterns that are necessary for community building and health improvement. Structural networks and processes that nurture and maintain these traits, resources, and patterns are also inherent to community capacity. Of equal importance are the perceptions, skills, and resources of individuals that are channeled through these social structures (Norton et al., 2002).

Across informants, specific themes emerged and all dimensions of community capacity were addressed at differing points throughout the data; through informants or secondary data analysis. Table 9 presents the GENESIS constructs studied, community capacity dimensions with subdimensions that were evident within the data for each construct. The specific themes that emerged for each dimension of community capacity theory is also outlined in order to establish linkages between the data and existing theory.

GENESIS Constructs • **Identified Themes**	**Community Capacity Dimensions**	**Community Capacity Subdimensions**	**FG 1**	**FG 2**	**KI 1**	**KI 2**	**KI 3**	**PO**	**Secondary**
<u>Culture</u> • Functionality	Skills & Resources	• Skills • Resources (financial, technological, other material)	X	X	X	X			X
• Functionality	Learning Culture	• Understanding of community history • Critical reflection	X	X	X	X	X	X	
<u>Community</u> • Individual Responsibility	Value System	• Community values	X	X	X	X	X	X	
• Collective Responsibility	Civic Participation	• Participation • Distribution of community power	X					X	X
• Collective Responsibility	Leadership	• Leadership						X	
• Collective Responsibility	Social Relationships	• Sense of community • Social capital/trust	X	X	X	X	X	X	X
• Functionality	Community Dialogue	• Social & interorganizational networks • Mechanisms for communication across the community & for citizen input							X
<u>Health Services</u> • Practicality • Perceived Quality	Skills & Resources	• Skills • Resources (financial, technological, other material)	X	X	X	X	X	X	
• Trustworthiness	Social Relationships	• Sense of community • Social capital/trust	X		X		X		X

Table 9: Community Capacity Dimensions identified by Data Type

Organizing Theme: Functionality

Functionality was evident throughout the construct of culture for a number of reasons. Throughout all levels of the data, it was established that being active and able to work are measures of health. The community's history establishes the community as an agricultural community; supporting both farming and ranching. These industries require people that are going to get up in the morning and go to work. These ideals have been well supported throughout rural literature. Bushy (2000) explains rural dwellers define health primarily as the ability to work, be productive, to do usual tasks. There are two community capacity dimensions that are evident in this theme of functionality. These include: Skills and resource and learning culture.

Skills and resources.

The importance of skills and resources was seen throughout all levels of data. The community history confirmed the skills and resources of agriculture sustaining the community. Focus group members discussed it simply as the ability to be active or being able to get up and go to work. For key informants it was mentioned as being able to take care of your family. Interestingly enough, skills and resources didn't only have to do with working. It also had to do with self-determination or being able to do what one desires and to the level they are capable of. This could possible speak to the increasing number of retirees and elderly in the community.

Learning culture.

The second dimension that emerged within functionality is learning culture. Learning culture encompasses an understanding of community history coupled with

critical reflection. The majority of the participants have lived in the Willcox community for more than 20 years. Due to this longevity in the community, you gain a true understanding of the community's history. Focus group one had several members that critically reflected on the community's history of not wanting to take responsibility for themselves and being "dormant" when it came to health and taking care of their bodies. They also discussed the culture of "enabling". These reflections reverberated throughout the second focus group with reflection on the community's youth and lack of responsibility on both the parents and child's part. Key informants also took on critical reflection in regards to choices people make regarding their health and lack of self-care. Finally, the participant observations yielded community organizations with a true understanding of the community's history, health issues, and needs – an indication that they have reflected on the community's current position and the need to learn from past experiences.

Organizing Theme: Individual Responsibility

Individual responsibility was evident throughout the construct of community in a number of ways. In relation to community capacity theory, this was seen in the value system. Throughout the data, it was established that community health starts at the individual level. This speaks to the value system of the community, and thus the community capacity dimension of value system.

Value system.

Values were spoken about across all levels of data. Focus group one spoke about the community's health starts with the simple things one does at home. Focus group two

spoke more generally about parents and their responsibility to ensure their children get proper nutrition and exercise and their health is determined by their actions and decisions. Whereas, the key informants spoke about the responsibility everyone has to have healthy habits to ensure the health of the community. Participant observation revealed many community leaders citing a personal responsibility to self-care.

Organizing Theme: Collective Responsibility

Collective responsibility was evident throughout the construct of community. As it pertains to community capacity theory, collective responsibility plays into the dimensions of: Civic participation, leadership, and community dialogue.

Civic participation.

Civic participation involves community participation and distribution of community power. This is evident in the secondary data analysis with the makeup of the local hospital board being primarily community members. It was also evident in attending the community meetings that the members of these groups felt a strong sense for the need to be involved at the community level. Focus group one spoke about the need for civic participation and volunteering at the community center so the elderly would have a place to meet, interact, and receive social and health services.

Leadership.

Leadership is integral to any community and it is a component of the Willcox community. "Leadership" is defined as "the office or position of a leader" and "capacity to lead" (Merriam-Webster Dictionary Online, 2009). This was witnessed in the community forums, where community members were elected into leadership positions to

guide their particular entity. The majority of these leaders were accepting of the researcher into their meetings and were more than willing to discuss the community's health. Conversely, two of the community forums were reticent to speak publically about health issues due to a perceived acceptance of responsibility for the issues. One community forum did not allow the researcher to attend their meeting as it was the opinion of the leader that community health is not a concern of their organization. Whether or not these positions shows a lack of leadership is a matter for debate; however, it is the opinion of the researcher that in order to lead a community, one must first be willing to acknowledge and speak about the issues and needs at hand and accept the reality that community health is everyone's responsibility.

Community dialogue.

Community dialogue is centered on social and interorganizational networks with mechanisms for communication across the community and for citizen input. This was evident in one piece of the data – historical background of the community, more specifically the history of health services. In addition, throughout the participant observations, there was limited community members at the public meetings. The exception was the local hospital board meeting. This was perceived by the researcher to be in relation to the threatened closure of the nursing home by the past administrator and board. This representation, as outlined in Chapter Four, is the perfect example of the potential breakdown of community dialogue and the importance of keeping channels of communication open between leaders, organizations, and citizens. In this instance, the

citizens of the Willcox community demonstrated their capacity to pull together and be proactive for the safety and betterment of the entire community.

Organizing Theme: Trustworthiness

Trustworthiness was evident throughout the construct of health services in a number of ways. It was discussed in terms of loyalty to health providers for providing knowledgeable care, providing a personal touch to care given, and the degree of community engagement. In relation to community capacity theory, trustworthiness is evident in the social relationships that are built.

Social relationships.

Social relationships within a community provide a sense of community and build social capital and trust. This was evident throughout the data, at all levels. Secondary data analysis revealed the local hospitals dedication to being a part of the community. This builds not only trust but social capital for the institution. Focus groups revealed a true sense of appreciation to local providers for being engaged in the community and being "human", Key informants stated the need to know the local providers and for the providers to know their patients on multiple levels (professional, social, familial) as it makes the care received better due to familiarity.

Organizing Themes: Practicality

Practicality was evident throughout the construct of health services in two primary ways: 1) the need for lost cost care and 2) the need for specialty care. It was discussed in terms of not having insurance, having insurance but only able to use certain providers,

and distance to care that requires traveling and therefore cost. This theme is central to the skills and resources dimension in community capacity theory.

Skills and resources.

This dimension speaks to the financial and technological resources available to people within the community. Those without insurance or have to travel a distance to receive care are faced with evaluating their financial resources. Those that need specialty care and the technology that comes with that care are faced with evaluating the technological resources of the community.

Organizing Theme: Perceived Quality

Quality of care is currently a hot topic in healthcare circles. As discussed in Chapter One, the quality initiative has reached rural America with the goal of decreasing the effect disparities have on rural dwellers. These disparities are related to access to care, quality, and service utilization (Ricketts, 2002).

Skills and resources.

Perceived quality emerged as a theme in the construct of health services. It was discussed in relation to how local providers treated them, knowledge level of providers, and use or misuse of technology. These perceptions align very well with community capacity theory's skill and resources dimension. As previously mentioned, this dimension is concerned with skills of local workers and the resources available (financial, technological, other material). The data points vividly to the skill level of local providers and the technology available locally.

Community Capacity of a Rural Southeastern Arizona Border Community

Through this analysis, it has been determined that community capacity is adequate in the Willcox community in the constructs that were investigated: culture, community, and health services. This is evident with all dimensions of community capacity theory emerging within the identified themes. Future work may continue this community assessment into the other constructs of the GENESIS model and assessing community capacity.

Integration with Rural Nursing Key Concepts

In Chapter Two, a proposed middle-range theory for rural nursing was discussed. The need for further validation is necessary before it can be applied across the diverse rural continuum. Previous rural nursing studies conducted have assessed communities along the US-Canadian border (Lee, 1998; Lee & Winters 2006) or rural Southeast (Bushy, 2000). To date, studies are lacking along the US-Mexico border as to whether these concepts generated in the north and southeast hold true for this diverse region. This being the secondary aim of this study: To compare the findings of this study to previous studies, models, and theories of rural nursing and rural health.

As previously discussed, rural nursing key concepts include: 1) distance, 2) isolation, 3) lack of anonymity, 4) familiarity, 5) old-timer, 6) newcomer, 7) insider, 8) outsider, 9) self-reliance, 10) health resources, and 11) informal networks. These are discussed individually below and how they emerged in this study. Table 10 provides a summary of which data sources revealed each key concept.

Rural Nursing Key Concept	Local Users of Health Services Focus Group	Local Nonusers of Health Services Focus Group	Key Informant 1: Tiffany	Key Informant 2: Drake	Key Informant 3: Wendy	Participant Observation
Distance	X	X	X	X	X	X
Isolation	X	X	X	X	X	X
Lack of Anonymity	X		X			
Familiarity	X	X	X	X	X	
Old-timer / Newcomer	X	X	X		X	
Insider / Outsider	X	X	X		X	X
Self-reliance	X	X	X	X	X	X
Health Resources	X	X	X	X	X	X
Informal Networks	X		X		X	

Table 10: Rural Nursing Concepts Identified by Data Source

Distance

Distance influences the delivery and receiving of care and is measured in three ways: 1) mileage, 2) time, and 3) perception of distance. The concept of distance was evident throughout all data levels. Distance was described as mileage and time from local and out of town services. It was also discussed in terms of perception and how it is worrisome to have something wrong and having to travel the distance not knowing how serious their child's condition was. It was also spoken about as a barrier to care during all discussions in terms of the inability to travel the distance (mileage and perception of distance) and the need for prompt care (timeliness).

Isolation

Isolation can be either geographic or social. Geographic isolation effects health care quality, utilization, and access to patients. A consequence of geographic isolation can be loss of health, limb, or even life. Geographic isolation was mentioned throughout

the data with many participants stating they lived too far out of go to the doctor and not having anyone to take care of them because they don't have any neighbors. Another participant mentioned being in the middle of nowhere and her friend collapsing and having to do CPR. Both of these examples are congruent with isolation.

Social isolation results in decreased communication and interaction with other people. This is true of one participant that cited her closest neighbor being two miles away. Other participants spoke about the elderly in the community and their inability to get out of their homes and lack of senior services that would solve isolation issues.

Lack of Anonymity

Lack of anonymity encompasses taking care of patients that are known outside the client/nurse relationship. In order to have lack of anonymity, the nurse must be visible, identifiable, and smaller boundaries (both professional and personal). This was demonstrated throughout the data with lack of anonymity being seen as a positive. Healthcare providers that lived locally were viewed as "human" and more approachable.

Familiarity

Familiarity is described as healthcare providers getting to know the patient like they are family. Providers with familiarity are seen focusing on total care because they get to them like a person. Patients become friends, neighbors, or relatives. This results in highly personal care due to the provider's familiarity with patients. Familiarity was mentioned multiple times throughout the data describing them to be known in many circles (professional, social, familial). According to participants, this made them better providers of care, increasing their trustworthiness.

Old-timer, Newcomer, Insider, Outsider

The phenomena of old-timer/newcomer and insider/outsider have been discussed throughout the rural literature. Old-timer/newcomer are defined by time lived in the community for which a clear cut delineation is lacking; whereas, insider/outsider are well defined. Insider status is determined by length of residence, family history, and type of occupation with the following key attributes: access to privileged information constitutes power, those with an awareness of implicit assumptions and social context are reserved social positions, and long-time residents of the community. Conversely, outsiders are lack a comprehension of social context, beliefs, rituals, customs, and history of community. For this reason, they are often are excluded from accessing community information and knowledge. Outsiders are not accepted, are not recognized, isolated, and distrusted by community members. Key attributes of outsiders include: differentness in terms of cultural orientation, standards, lifestyle, education, religion, occupation, social status, world views, interests, and experiences; unfamiliarity with community; and unconnectedness.

These concepts emerged throughout the data to varying degrees. Keep in mind that only those that have lived in the community for a minimum of five years were allowed to participate. During the key informant interviews and focus groups, the PI noticed a sense of pride in those that had lived in the area for more than 20 years with many participants stating, “I’ve lived here all my life”. Many of the participants spoke of things that had occurred 30-40 years ago which provided an air of nostalgia and a true sense of what “old-timer” means.

The concepts of insider/outsider emerged throughout the data and appeared to be a source of strain on the community. Many participants talked about not liking the emergency department doctors because they had no ties to the community or lacked a vested interest in the community. They were described as coming in, providing a service, collecting their money, and leaving. Even those that were reportedly nonusers of local services discussed the importance of local providers living in the community and being engaged.

Self-reliance

Self-reliance is the desire to do for oneself and care for oneself. Those that are self-reliant view the individual as responsible for health knowledge and care. They are resistant to care from outsiders and will seek health information and assistance from local, often informal sources. Key characteristics include: independence, self-determination, individuality, and privacy. Self-reliance played out in many ways throughout the data. First, the notion of self-determination emerged through the theme of functionality and a person's ability to be active. Second, independence and individuality emerged in the theme of individual responsibility regarding personal and community health.

Health Resources

Health resources are centered on the allocation, accessibility, and utilization of services. This concept acknowledges that rural communities have a maldistribution of health professionals and barriers to accessing care (transportation, distance, inclement

weather, finances). It also acknowledges the need to increase awareness of services locally, regionally, and nationally.

Maldistribution of services was evident throughout the data at all levels with all groups identifying the lack of specialty care. Barriers to accessing care were also discussed in regards to lack of transportation, distance to care, and the affordability of getting to the service and paying for it.

An interesting dichotomy emerged in regards to community awareness. Throughout the participant observation at community forums, all cited their role to ensuring community health is ensuring community members are informed of services offered and potential hazards to health. Both focus groups and all key informants cited ensuring awareness of services and potential hazards to health is the job of community leaders, but they did not feel it was being done. It is not clear to the PI why this dichotomy exists, however it warrants further investigation.

Informal Networks

Often times the rural people will turn to informal networks to help in decision-making regarding health and wellness (Weinert & Long, 1991). Informal networks are present throughout every aspect of human life and play an integral role in our existence. Often times these networks in rural America are seen as safety nets for rural clients that are "falling through the cracks" of formal health care provision (Grossman & McNerney, 1998). Informal networks are centered on volunteerism, information exchange, support, and guidance. These networks were found to exist in the data with mention of helping neighbors and being neighborly. It was also seen in the local users of health services

focus group where one woman talked about how the community center could be opened with the help of volunteers for the elderly to receive social and health services – providing a meeting place to interact. In this example, the informal network was an answer to one of the perceived issues of the community – senior services.

Onward to Building a Middle-Range Theory for Rural Nursing

It is evident from this analysis that the rural nursing concepts proposed by Lee (1998) and Lee & Winters (2006) do in fact exist along the US-Mexico border or the southwest US. Although there are other regions of the country this emerging theory must be validated on before it is called theory, this study has added to the rural body of knowledge and will aid in the progression of theory development.

Strengths and Limitations of the Study

The strengths and limitations of the study must be acknowledged prior to delineating implications of the findings for subsequent practice and research. A key strength of the study was the depth of information provided by the participants through interviews. Their openness, willingness, and perspectives provided rich data that told their experiences and perceptions. They also provided meaningful and significant suggestions for improving the health of the Willcox community. A second strength was the embeddedness of the researcher. The researcher's education and experience helped maintain a level of objectivity and neutrality. Further assurances were taken by the use of an outside observer to ensure the researcher obtained an etic viewpoint during focus group and participant observations. In addition to the audit trial and outside observer, an expert methods consultant was used to corroborate the interpretive process which

increased the researcher's objectivity. Conversely, familiarity with the community facilitated the interviews; informants were open and in-depth in their responses to questions. A third strength was that the sources of data crossed various levels of community – from individual, to group, to community-wide levels. The final strength of this work is the strong connections made with community leaders and members. This community engagement with the researcher will aid and possibly instigate future work that needs to be done regarding community health.

A limitation, of necessity, was the focus on one rural community. Although a rural southeastern Arizona border community was the focus, the degree of transferability must be questioned. The Willcox community's strong agricultural background may differ from findings across rural communities, even in Arizona, that have their economic bases in mining, tourism, or retirement. Another limitation included excluding the Hispanic/Latino group that speaks Spanish as their primary and only language. Due to this study being an introductory work, the PI felt including this group into the study would require further cultural expertise and considerable investment to achieve the necessary level of trust. With including this group into the study, a cultural broker and interpreters would be used and access to a potentially illegal group of migrants would be tenuous. As the researcher continues community engagement, the opportunity may present itself in future work. Also, Arizona is well known for its Native American population and a large percentage of rural land in Arizona is occupied by reservations. Although this population was not excluded from the study, lack of participation was obviously due to proximity of Willcox to a reservation. A final limitation, through

limiting the number of GENESIS constructs evaluated, a limited view of the Willcox community resulted. Although this limitation was out of necessity, future work may include all GENESIS constructs.

Implications for Nursing Practice

From the onset of this work, the researcher has cited the purpose behind this study being the need for rural nurses to be proactive in knowing their community; to ensure the provision of culturally competent and valuable health services, while increasing community awareness. For rural nurses, it is not as simple as picking up a book on rural nursing and from this gain understanding of rurality. Rurality is a diverse continuum that requires each individual nurse to become engaged in their own community; tailoring health care services and culturally competent care to the needs of their community. This study has shown the importance of community assessment as a first step in providing and building valuable and sustainable health services.

An example, as it pertains to advanced nursing practice is the researcher's clinical work in the community. The researcher has worked professionally in the community for four years as a family nurse practitioner. During the first three years she was an employee of the local hospital. One year ago, with the aid of a local physician and physician's assistant, the nurse practitioner opened a collaborative private practice. This study has proved to be an eye opening experience for the researcher, not only as a researcher, but also as a clinician that is attempting to provide valuable, sustainable, and culturally competent care as a business owner. The vision statement of the clinic sums up

this mandate felt by the three providers in this endeavor, “Where patient-centered care and community come together”.

This speaks to the findings of this study regarding trustworthiness and perceived quality. Many participants spoke about their local provider being familiar with them and them knowing the provider outside the patient/provider relationship. It was spoken about in terms to knowing the provider in social situations, seeing them at the grocery story, and knowing their family. In this community, trustworthiness and perceived quality are not only measured by what is done in the clinician’s office, it is also measured by community engagement and it cannot be underestimated by local providers of care. If advanced practice nurses are to be successful and provide competent care in rural communities, they must be engaged. From these findings the PI will continually evaluate her community engagement and seek opportunities to maintain visibility and accessibility to community members.

A result of the community engagement obtained by the PI in this study has immense implications for not only her private practice; but also the greater healthcare team in the community and those that reside in Willcox. In Chapter Three, community capacity theory was discussed as it related to the Project GENESIS methodology. Critical inquiry is a main component of this methodology and it is the next step in continuing this research study. Although this touches on research implications, this critical inquiry requires action and in many ways can be viewed as an intervention at the community level as it engages the community as partner to act on identified health needs and issues.

In order for health services to be used locally, local service providers and leaders must be made aware of the health culture, beliefs, and actions of the community members'. This must be done by taking the findings of this study to community leaders and healthcare providers to initiate dialogue between members of the community. From this dialogue, it is anticipated several things could happen. First, local leaders will have the ability to make more informed decisions regarding health and healthcare in the Willcox community – making them more relevant and culturally competent. Second, it is anticipated that through partnering with the community the doctorally prepared advanced practice nurse may have the opportunity to develop a Willcox Health Consortium, where community leaders, citizens, healthcare providers, and the advanced practice nurse can sit at the same table and act as a support and instigate change of local health services. This process will result in a community that feels valued and heard; leaders that are more informed and cognizant of the health issues; health service providers that are utilized, relevant, and culturally competent; and overall enhances community health and well-being.

Implications for Nursing Research

From this work, it has been determined that important work needs to be done both within this community and throughout rural communities nationwide. Much of this study reinforces the theories and concepts of rural nursing that have been proposed by Bushy (2000), Lee (1998), Lee & Winters (2006), and Long & Weinert (1989). Although there are other regions of the country the emerging theory must be validated on before it is

called theory, this study has added to the rural body of knowledge and will aid in the progression of theory development.

During the course of this work an interesting dichotomy emerged in regards to community awareness. Throughout the participant observation at community forums, all cited their role to ensuring community health is ensuring community members are informed of services offered and potential hazards to health. Both focus groups and all key informants cited ensuring awareness of services and potential hazards to health is the job of community leaders, but they did not feel it was being done. It is not clear to the PI why this dichotomy exists, however warrants further investigation.

Through this analysis, it has been determined that community capacity is adequate in the Willcox community in the constructs that were investigated: culture, community, and health services. This is evident with all dimensions of community capacity theory emerging within the identified themes. Future work may continue this community assessment into the other constructs of the GENESIS model and assessing community capacity.

Specific Recommendations for Future Research

At the onset of this work critical inquiry was to be a component of the work and it is in fact part of the GENESIS model. Due to this being an introductory work, the removal of the critical inquiry piece was backed by all committee members and the expert methods consultant. Now that the researcher has learned about this community, the next step would be to bring the findings back to the participants, community members, and leaders to promote action on the identified issues. This process would

allow further insight into the community capacity and potentially lead to action. From this dialogue, it is possible a community health taskforce would be created to tackle the issues at hand and ensure every member of the Willcox community is allowed to reach their desired level of health and well-being.

Conclusion

This study was guided by two aims. The first aim was to conduct a community assessment with ethnographic principles centered on definitions of health, access to care, quality of care, and health needs and issues. This was achieved in terms of learning about the meaning of health and factors that enhance or impede care. The second specific aim was to compare these findings to previous studies, models, and theories of rural nursing and rural health. This was accomplished through critically examining discussions held during focus groups, key informant interviews, and participant observations while looking at the key concepts of rural nursing.

The process and outcomes of this study revealed there is a lot to learn about one's community and it is essential to take on this learning role to ensure the care provided is trustworthy, high quality, and practical. Ensuring these factors will enhance service utilization, access to care, and ultimately quality of life. Through this work, it was identified that community members feel an individual and collective responsibility to the community to ensure its own health. It is felt the doctor of nursing practice degree coupled with the advanced practice nursing role provides these nurses to be optimally prepared to learn of their communities by its members and leaders. It is from this

preparation and engagement that relevant change can occur in the provision of health services rurally nationwide.

APPENDIX A

DIMENSIONS AND SUBDIMENSIONS OF COMMUNITY CAPACITY BY GOODMAN ET AL. (1998)

Dimension	**Subdimension**
Participation	• Strong participant base • Diverse network enabling diverse interests to take collective action • Benefits overriding costs associated with participation • Involvement in defining/resolving needs
Leadership	• Inclusion of formal/informal leaders • Provide direction/structure for participants • Encourages participation from diverse networks of community • Implements procedures for ensuring participation from all participants • Facilitates sharing of information • Shapes/cultivates new leaders • Responsive/accessible style • Focus on task & process details • Receptivity to innovation & risk taking • Connectedness to other leaders
Skills	• Engage group processes, conflict resolution, collection & analysis of assessment data, problem-solving & program planning, intervention design and implementation, evaluation, resource mobilization, policy & media advocacy • Ability to resist opposing/undesirable influence • Attain optimal level of resource exchange
Resources	• Access/sharing internal/external resources • Social capital/generate trust, confidence, cooperation • Communication channels within/outside community
Social & Interorganizational Networks	• Reciprocal links throughout network • Supportive interactions • Overlap with other networks within community • Ability to form new associations • Cooperative decision-making processes
Sense of Community	• High level of concern for community issues • Respect, generosity, service to others • Sense of connection with place and people • Fulfillment of needs through membership
Community History	• Awareness of social, political, economic changes • Awareness of types of organizations, community groups, community sectors present • Awareness of community standing relative to other communities
Community Power	• Ability to create/resist change re: turf, interests, experiences • Power with others, not control over them • Influence across domains/contexts
Community Values	• Clearly defined norms, standards, attributes • Consensus building about values
Critical Reflection	• Ability to reflect on assumptions underlying others' ideas/actions • Ability to reason logically & scrutinize arguments for ambiguity • Ability to understand forces in environment influence both individual & social behavior • Ability for community organizations to self-analyze their efforts at change over time

APPENDIX B

DIMENSIONS AND SUBDIMENSIONS OF COMMUNITY CAPACITY BY NORTON ET AL. (2002)

Dimension	**Subdimension**
Skills and resources	• Skills • Resources (financial, technological, other material)
Nature of social relationships	• Sense of community • Social capital/trust
Structures and mechanisms for community dialogue	• Social and interorganizational networks • Mechanisms for communication across the community and for citizen input
Leadership	• Leadership
Civic participation	• Participation • Distribution of community power
Value system	• Community values
Learning culture	• Understanding of community history • Critical reflection

APPENDIX C

INTERVIEW GUIDE

Opening questions:

Tell us your name and how long you have lived in the Willcox area.

Why are you living in the Willcox area and what are your hobbies?

Questions relevant to contextual factors include:

Culture:

How do you define health?

How do you feel when you are well?

How do you feel when you are sick?

What do you do to stay well?

How do you define your community?

How do you think your community defines health or being well?

How would you describe your culture?

Does your culture consider health and/or healthy behaviors essential?

How do you think living in a rural community impacts health?

What are factors might protect someone from illness?

What are risk factors for illness? What makes it worse?

Community:

What is the community's responsibility regarding prevention of illness?

What factors in a rural community must be taken into consideration when assessing and implementing programs addressing health and wellness?

What are barriers to providing interventions for wellness in a rural community?

What do you think community members and those in positions of authority and those who act as providers see as good health in individuals and the community (or in a well person/community)?

What are the characteristics of rural residents that influence health care?

What are factors of rural communities that influence health care?

What is it about a rural community that makes health care delivery different?

What does health, wellness and illness mean to you?

The following two questions to be answered on demographic questionnaire:

What are the top five health issues facing this community?

What are the top five health needs of the community?

How are these issues/needs currently being addressed?

Health Services:

Is individual and/or community health valued at the community level and in what forums is it discussed?

What barriers influence seeking health care?

What do you look for when seeking healthcare?

What is your perception of local health services and why?

Where and how do you currently access health services?

In what way does your accessing health services impact your life?

In your opinion, what can be done to aid your access to health services?

Conclusion of interview:

Any final comments:

What is unique about health and wellness in rural communities and how can that best be addressed?

I am trying to understand the health issues facing our community to promote change. What advice do you have for me?

Is there anything that we should have talked about but didn’t?

APPENDIX D

INFORMED CONSENT FORM

Project GENESIS: Community Assessment of a Rural Southeastern Arizona Border Community

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of the signed consent form will be given to you.

What is the purpose of this research study?

The purpose of this project is to increase understanding of health and access to health services within the context of a rural community and to identify factors that may influence health and well-being.

Why are you being asked to participate?

You are being asked to participate because of your unique knowledge and experiences in the Willcox community. To be eligible to participate, you must be 18 years of age or older, able to speak English, and have lived in the Willcox community for a minimum of five years. Both men and women are being invited to participate that are from all ethnic backgrounds.

How many people will be asked to participate in this study?

A total of 25 individuals will be enrolled in this study locally.

What will happen during this study?

Once you have agreed to participate in the study, you will sign this informed consent and disclosure form. You will be reminded of your meeting with the Principal Investigator one day prior by telephone. You will participate in <u>one</u> of two focus groups (2-3 hours) or an individual interview. These sessions will be held in a private location to assure confidentiality and audio taped for later transcription. Your name will appear on the consent, and then a code name will be assigned for tapes and transcriptions. You may also be asked to participate in the validation process which would entail a second meeting

with the Principal Investigator. As data are analyzed, the results will be shared with participants in focus groups and individual interviews to assure the accuracy and validate the information obtained.

Please check one:

_____ I give my permission to participate in the validation process.

_____ I do not give my permission to participate in the validation process.

How long will I be in this study?

Your participation in this study may last up to four months (December through March). During these four months you will participate in one focus group and may be contacted at a later date for validation (anytime between January and March).

Are there any risks to me?

There are risks associated with an increased awareness of a health issue such as use or underuse of health services in one's own community. If participants become aware, they may feel responsible for addressing these issues, leading to sociological and psychological risks. Participants are also at risk of learning about themselves in regards to personal and community health. If this occurs, and you are uncomfortable, you may choose to stop participating immediately.

Due to this study being conducted in a rural community, other community members may learn of your involvement in this study. The risk associated with focus group sessions and follow-up questioning will be minimized through conducting the sessions in a common everyday setting at a local hotel conference room. Individual interviews will be conducted in a place of your choosing to ensure comfort and privacy. If you are asked to be involved in the validation process, this will be done in a place of your choosing to ensure comfort and privacy.

Are there any benefits to me?

There is no direct benefit to you from your participation. There is the benefit of increased awareness of the factors influencing health and access to health care in your community.

Will there be any costs to me?

There is no cost to you for participating except your time (approximately 2-3 hours for involvement in one focus group or individual interview).

Will I be paid to participate in the study?

You will not be compensated for your participation.

Will video or audio recordings be made of me during the study?

We will make an audio recording during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

☐ I give my permission for audio recordings to be made of me during my participation in this research study.

☐ I do not give my permission for audio recordings to be made of me during my participation in this research study.

Will the information that is obtained from me be kept confidential?

The only persons who will know that you participated in this study will be the research team members: Amanda D. Bennett, Principal Investigator; Cindy Clement, focus group moderator; Diane Thomas, outside observer; and focus group participants.

All study materials will be kept confidential. You will not be identified in any reports or publications resulting from the study. It is possible that representatives of the sponsor that supports the research study will want to come to The University of Arizona to review your information. Representatives of regulatory agencies (including The University of Arizona Human Subjects Protection Program) may access your records.

All study materials obtained will be kept in a locked file cabinet in the Principal Investigator's personal office. Information that may identify any one individual, group, or situation will be blended to create a composite for confidentiality as findings from this study are reported.

May I change my mind about participating?

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Your refusing to participate will have no effect on you or your health care. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

Whom can I contact for additional information?

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal Investigator Amanda D. Bennett, DNP

candidate at (520) 955-3343. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the research team, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web, please visit the following website: http://www.irb.arizona.edu/contact/.

Your Signature

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

_____
Name (Printed)

_____ _____
Participant's Signature Date signed

Statement by person obtaining consent

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

_____
Name of study personnel

_____ _____
Study personnel Signature Date signed

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