

FROM BENCH TO BEDSIDE: PUTTING PRACTICAL ETHICS ON THE ROAD  
IN RURAL NORTH CAROLINA

BY

M. LISA HAMMON

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Approved by:

Nancy M.P. King, Advisor

Michael J. Hyde, Chairman

Rosemarie Tong

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## ABSTRACT

Spectacular achievements in diagnostic and therapeutic medical technology, beginning in the mid-20<sup>th</sup> century, opened the door to both medical progress and the inherent moral ambiguities and potential harms co-existing with that progress. Technologies like CPR and mechanical ventilation created new ethical minefields for medicine and society. Bioethics grew out of efforts to understand and manage the issues of conscience raised by these new therapies. Although it now has a national presence and a large footprint in academic health care, bioethics has a minimal presence in small rural and community hospitals, which serve nearly a third of the American population. Rural hospitals and rural professionals face a unique set of ethical challenges stemming from the characteristics of rural culture and limited access to technology, continuing education, and supportive resources like bioethics training and expertise. In this thesis I explore these challenges. I examine ethics networking as a vehicle for reaching out to rural providers with ethics education, training and consultative services. I survey several rural hospitals with a *de novo* instrument created to assess their needs for ethics resources and to gauge their interest in the network concept. Finally I offer a proposal for the development of an ethics network that would link the deep ethics expertise in academia with rural hospitals that lack access to ethics resources.

## Chapter 1. Introduction: Bioethics in Healthcare

In the early 20<sup>th</sup> century spectacular achievements in diagnostic and therapeutic medical technology, including mechanical ventilation and cardiopulmonary resuscitation (CPR), opened the door to extending life artificially. Inherent moral ambiguities and potential harms co-existed within this growing armamentarium, setting out new ethical minefields for medicine and for society. Peter Medawar summed up this notion saying, “The mischief...grows just as often out of trying to do good...as out of actions intended to be destructive”.<sup>1</sup> Throughout the mid and late 1960s a great debate about issues of conscience in modern medicine gained a multidisciplinary foot hold in academic forums across the country. Important thinkers of the day, among them Leake, Gustafson, Ramsey, Kaplan, Callahan, and Joseph Fletcher, confronted the ethical challenges presented by medical advancement. In the early 1960s these scholars engaged the medical establishment in what was to become a multicultural discourse surrounding emerging moral concerns. In the four decades since, scholarly study of bioethics has broadened and is now prominently and persistently engaged in the ongoing national debate about the moral boundaries challenged by manipulating the human body using biological technology.

Large academic medical institutions, whose missions include both scientific and scholarly study of healthcare disciplines, including bioethics, have served as fertile training grounds for institutional ethics committee members over the years, thus supplying ethics prepared practitioners to their home institutions. However, academia has not done a good job of placing ethics prepared practitioners in non urban areas.

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<sup>1</sup> Quoted by conference Chairman Daniel Labby in opening remarks at conference, “The Sanctity of Life” held by Reed College, Portland, Oregon 1966. Dr Medawar was also a speaker at that conference

Bioethics frames the examination of moral dilemmas routinely encountered in the day to day commerce of institutional healthcare regardless of a hospital size or setting. While the application of bioethics to health care has a significant national footprint, bioethics continues to have a minimal presence in health care domains outside of academic medicine, particularly in rural community hospitals. It could easily be anticipated that moral and ethical dilemmas would be frequent and pressing in academic medical centers which often function as frontier test sites and proving grounds for leading edge technologies. Less obvious, perhaps, are ethical problems encountered in small rural community hospitals which, though quite different, are of an equally pressing nature. That bioethics partnerships are rare in non academic hospitals will not come as a great surprise to many who are scholars and clinical practitioners of bioethics.

We have learned that ethical issues confronting health care providers are challenging and the pathways to resolution of ethical conundrums require a certain awareness that is typically of characteristic specialties other than medicine, such as philosophy, religion, and law. However, 'doing ethics' in a hospital setting requires negotiation of systems that operate on a thought framework that is quite different from the thought framework of philosophical ethics thus there are many barriers to making bioethics part of the hospital medical team's thinking. Successful incorporation of bioethics in routine hospital operations is often attributed to champions who persistently pressed forward despite institutional reluctance. Any hospital that utilizes modern technology such as mechanical ventilators and advanced diagnostic imaging will routinely run up against the moral juxtaposition of decisions to prolong life versus allowing death to proceed. Rural community hospitals are no exception. Typically remote from the resources and benefits of urban America, hospitals in rural locations are

challenged by unique problems in health care delivery such as thin physician rosters, few subspecialist practitioners, limited technology, and limited access to a labor pool of trained staff and leadership.

Bioethics expertise is a necessary component for the appropriate care of hospitalized patients in the high tech environment of health care today. Lack of this resource may diminish quality of patient care, drive up costs of health care and increase moral distress among health care providers leading to increased attrition of trained staff. Bioethics resources can be made accessible to rural communities by establishing a network system designed using knowledge of the unique characteristics of rural America as its blueprint. In this thesis I address the lack of bioethics resources in rural areas and discuss characteristics and culture of rural America. These cultural and demographic characteristics drive a particular set of ethics support needs which differ significantly from applied ethics in urban settings. While basic ethical tenets are virtual universal standards, rural hospitals think differently about their meaning in a rural community setting. These differences and the unique ethical problems encountered in rural healthcare settings will be explored in depth in the following pages. Challenges of "doing ethics" in a rural context, including the hardships posed by lack of knowledgeable, trained ethicists, financial constraints, and barriers created by rural culture will be outlined. I propose tools that can be used to assess the need for ethics support in individual community hospitals. I use some of these tools to conduct an ethics needs assessment of selected rural North Carolina community hospitals and from the data collected will describe education strategies to address them. Finally I recommend a methodology for how rural community hospitals could be engaged to participate in a network, how and by whom ethics resources could be delivered to

prospective members, and I discuss infrastructure necessary to begin and sustain a network.

### Summary of Chapters

Chapter 1. Introduction to Thesis Project: *From Bench To Bedside: Putting Practical Ethics On The Road In Rural NC.*

Chapter 2. Societal And Ethical Issues In Rural Healthcare. This chapter includes an in depth review of the literature that is specific to the intersection of ethics and health care in rural cultures. I describe how characteristics of rural culture affect not only healthcare delivery systems, but also professionals who provide healthcare services in rural areas. Defining differences between rural and urban hospitals, I discuss ethical challenges encountered in providing health care in rural areas.

Chapter 3. Demographic And Geographic Characteristics Of North Carolina. America is emblematic of cultural, racial and socioeconomic diversity. North Carolina, the 28<sup>th</sup> largest of the United States, has three geographical regions are distinct both geographically and culturally. Discussion of the state's demographic 'personality' and how these differences might affect choices in the development of a network strategy is discussed.

Chapter 4. Rural Ethics Networks In The US. Ethics networks are in operation in many areas of the US. History, characteristics and activities of several networks is discussed. A comparison is drawn of how operations differ between networks that have been successful over time and those that have been unsustainable.

Chapter 5. Assessment Of Hospital Needs For Ethics Services. Two rural hospitals agreed to participate in an assessment of their needs for ethics resources. Several instruments were designed and implemented to conduct a hospital staff assessment.

Surveys were sent to other rural or community hospitals to test their interest in network membership. Findings of these assessments are discussed and compared. Needs identified by the surveys are discussed and a plan for how resources might be delivered are described. A sample network mission statement is drafted to facilitate description of infrastructure that would be required to carry out the mission. Mechanisms of delivery of ethics services are suggested.

Chapter 6. Summary And Recommendations. Despite its strong educational and clinical presence in virtually all of America's academic medical centers, ethics has not moved far off campus. The establishment of an ethics network would allow linkage between bioethics experts in academia and rural community hospitals needing assistance with ethics education, policy writing, and clinical application of healthcare ethics. A network partnership between the Center and rural hospitals could provide on site research and practicum opportunities for students who wish to explore ethics in rural culture. Discussion and conclusions drawn in previous chapters informs a proposal to provide ethics resources to rural hospitals in North Carolina through a 'bioethics' network. Based on research of successful networks, recommendations are made for network infrastructure, fulfillment of needs for services identified in the research, and state demographics and geography.

## Chapter 2. Cultural Characteristics of Rural America & Rural Hospitals

Simply put, rural America is a collection of less densely populated areas which lie outside heavily populated metropolitan areas across the country. Most of America's land mass lies in rural territories; rural landscape accounts for nearly 75% of the land. According to the American Hospital Association (AHA) rural areas are home to about 72 million people (about 23% of the population).<sup>2</sup>

In general terms, rural America may be viewed as life outside the fast lane. Populations of rural areas are characterized by various settlement patterns dependent upon geographic location but they are otherwise similar in their ethos of independent individualism. Typically located on the 'by-pass' highways of America, these townships are often quite remote from metropolitan areas, lack public transportation, and thus the people in them experience challenges accessing services, goods, and benefits that urban dwellers take for granted. Social norms that are consistently characteristic of rural populations throughout geographic areas of the country include self-reliance, conservatism, work orientation, emphasis on family and religion, individualism, and distrust of strangers. A person is a stranger if he or she is not from 'around here'. A person who dresses differently speaks differently, or who behaves in a way foreign to the local folk will be thought of as a stranger, and will remain a stranger unless he or she is able to establish interactive relationships within the context of rural culture. Traditional gender roles are the norm in rural families and in the work force. In their article, *Voices from the Margins*, Cook and Hoas discuss the challenges outsiders encounter in a rural community and its health care environment.<sup>3</sup> Distrust of outsiders

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<sup>2</sup> American Hospital Association, (2010).

<sup>3</sup> Cook, A.F. & Hoas. H. (2001).

creates an additional barrier that affects the ability of non-local healthcare providers to impact the health care system.

The literature consistently describes rural populations as being at risk in several categories when compared with urban dwellers. Inhabitants of rural areas are reported to have higher rates of poverty, lower levels of educational attainment, challenges in access to goods and services, and social isolation. Higher rates of being under or uninsured are common to rural areas.<sup>4</sup> Rural populations tend to have a greater proportion of older adults. Certainly from a healthcare perspective, the rural population is a vulnerable population.

The ethics of rural culture is remarkably different than the culture of urban systems. Throughout the literature one is warned that attempts to 'flip' urban ethics practices to rural locations just don't work. Cultural mores, folkways, and lifestyles that define rural America require an approach to bioethics in health care that is unique. In small rural towns even the most densely populated neighborhoods are thin in comparison to tightly packed urban neighborhoods. Conventional wisdom would lead one to conclude that close quarters experienced in urban living would result in constant person to person exposure but in reality the nature of urban living affords a high degree of anonymity. People living in compact rural settlements, however, are exposed to one another on a day to day basis as virtually all commerce takes place in small business areas. Privacy takes on a different meaning to rural folk who often grow up in the community where they were born and raise their own families near neighbors they have known for a lifetime.

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<sup>4</sup> Multiple references noted in the bibliography document these findings.

The ethos unique to rural social cultures results in ethical challenges for rural healthcare providers that are different from those typically experienced by their urban counterparts. Predominant among these are maintenance of privacy and confidentiality, boundary setting and truth telling.<sup>5</sup> Privacy and confidentiality are made more difficult by overlapping relationships, dual roles, that are, in a sense, emblematic of small communities. Professionals living in rural towns are much more limited in terms of social privacy than their urban counterparts and are often engaged in roles of public authority and influence secondary to their professional stature in a small town. The nature of overlapping roles of providers who operate as private citizens in the community and their patients is at the heart of many ethical issues commonly encountered in rural community hospitals. The intimacy of rural life is a differentiator in terms of how core ethical principles are considered and managed when compared to urban settings.

Health care is often the dominant economic engine for a small town, employing the largest number of people and offering the greatest number of skilled job opportunities. Hospitals provide the structural and economic backbone for all other practitioners and health care entities in the community. When the employee roster is made up of friends and relatives of both the patient and the practitioner, privacy in a small community hospital becomes difficult to achieve. Boundary issues are an everyday challenge among providers who are typically engaged in multiple roles and in multiple relationships within the community. Competing roles which may hold different values in truth telling, duties, and expectations, affect this traditional ethical underpinning of the doctor-patient relationship. When a physician's golf buddy wants his friend the doctor

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<sup>5</sup> Nelson & Schifferdecker (2011).

to withhold the truth from his terminally ill mother, for example, the physician is caught between his relationship with his friend and fulfilling the moral and ethical duties of truth telling in his relationship with the patient. On the face of it this doesn't seem like much of a dilemma, but put in the context of a small, intimate society, the impact of this kind of emotionally laden decision making may have repercussions that are far reaching and long lasting.

#### Characteristics of hospitals in rural areas

Rural hospitals are frequently referred to as *community hospitals*. The use of the term community in this regard implies a social connection beyond the primary charge of serving the community's health care interests, a phenomenon well described by Cook and Hoas.<sup>6</sup> Community means something importantly different in these places and the community's hospital functions as a critical partner in local culture. Indeed, a community hospital will probably have unique qualities reflecting the values and cultural make up of its own local society. Rural community hospitals provide an important social venue for the populace they serve. They are gathering places for social congress and provide a public forum for multicultural societal interaction on topics from wellness to art. Rural community hospitals in a geographical area share much common ground in terms of economic and operational challenges yet, as microcosms of local culture, each is characterized by a 'personality' that reflects these unique values. They serve as anchors in the community much as the church did in times when there was only one house of worship to provide spiritual care in a small town.

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<sup>6</sup> Cook, A.F., Hoas, H. (2002)

The Health Resources and Services Administration (HRSA) has designated 77% of all rural counties as health professional shortage areas (HPSA).<sup>7</sup> In the US there are 2157 HPSAs in rural and frontier areas as compared to 910 in urban areas.<sup>8</sup> Most care providers, nurses and social workers, for example, are likely to be 'locals' or to come from a neighboring county. Physicians practicing in rural communities, however, are more likely to be imports, sometimes moving to the country in mid career. Opportunities for access to better technologies and higher earning potential offered by larger urban practices and hospitals are alluring for young physicians embarking on new careers, many with significant debt.<sup>9</sup> Likewise preferences for living in locales which provide access to more diverse social and cultural activities are deflecting physicians from rural areas to practice in urban areas where these opportunities are found. Physicians living and working in urban settings have social anonymity unlike those practicing in small rural hospitals where they are typically embedded in local societies and culture.

In contrast to their urban colleagues, the ability of rural physicians to be engaged in a relationship with the community is crucial to their professional success. A physician's demonstration of cultural competence in practice supports patients' willingness to receive health care in the community, and ultimately this behavior supports the economic stability of the hospital. Embedded characteristics of rural culture, particularly its intolerance of strangers, further constrain physician recruitment options, particularly affecting the large pool of foreign physicians who often have little understanding of diverse American cultures. A rural community is likely to reject a doctor who cannot accept and embrace its cultural ethos. Seeking and accepting

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<sup>7</sup> Health Resources & Services Administration.

<sup>8</sup> National Rural Health Association; what's Different about Rural Health Care? 2011.

<sup>9</sup> Position paper. (2011) American Academy of Family Physicians.

healthcare may be seen as inconsistent with commonly held values of self reliance and individualism embedded in rural culture. When such cultural phenomena are not recognized and no adjustments made to accommodate these into practice, the likelihood of the parties to enter trustingly into a doctor/patient relationship is reduced. In order to benefit the community and its local hospital a physician must practice and behave in a manner that enables the typical rural dweller to seek his or her care.

Historically, small rural hospitals in North Carolina were founded and often underwritten by local philanthropists, typically big businessmen in the county, who provided employment for local workers of all collar colors. Many hospitals continue to bear the names of the benefactors given in the old fashioned style of small town institutional labeling. Hugh Chatham Hospital in Elkin, founded by textile industrialist Hugh Chatham, is an example of maintenance of this very local designation. Fifty years later, the Chatham family continues to have a role on Board and in the hospital's Foundation. Recognition of this persistent and sometimes dogged intention to maintain its identity and legacy as a locally owned business to avoid the subtle communication of 'town and gown' superiority becomes a critical factor when considering networking engagements with a rural hospital. An example of this sensitivity to status was demonstrated during discussion with an ethics champion in a rural hospital when I referred to her hospital as 'rural'. She took umbrage at this term but, because of our history together, this champion understood that my intention wasn't to minimize and her correction was gentle but firm: hers, she clarified, wasn't a *rural* hospital it was a *community* hospital. Thoughtful consideration of such nuances of rural culture is important to construct relationships between academic/urban ethics representative and community hospitals.

Similar to their big sister hospitals in urban areas, community hospitals face the increasingly daunting challenge of providing health care when many they serve cannot pay. Additionally, rural populations have a disproportional rate of Medicare/Medicaid health care coverage which typically provides low-end reimbursement of medical charges. Unlike large hospitals that can generate income, for example by providing terrain for field research and clinical training, rural hospitals are very limited in what they can offer to attract outside capital. They are constrained by low patient volumes, higher rates of no-pay patients or low-paying insurers, and narrow profit margins.<sup>10</sup> Hospital leadership is periodically required to review its services to determine which will have to be abandoned in order to keep their doors open to the general community and maintain its priority healthcare needs. Congress has enacted programs and regulations that aim to protect these critical institutions which are often the only access rural communities have to healthcare. Designated as Critical Access Hospitals (CAH), Sole Community Hospitals (SCH), Medicare-dependent Hospitals (MDH), and Rural Referral Centers (RRC), these institutions have some governmental protections against healthcare budget cuts.<sup>11</sup> In this economy, however, even these small protections are at risk of being de-funded as healthcare costs continue to spiral upwards. However beneficial they might be to the staff of a hospital, 'soft' resources, (those not required by a high degree of visible need, regulation or law) such as ethics resources, are extremely vulnerable to being cut. At least the funding of ethics committees within small hospitals has some protection because of regulatory mandates that deem consideration of ethics in patient care as a critical need. The Joint Commission (TJC), for example, requires all hospitals it certifies to have a process for addressing ethical concerns regarding patients'

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<sup>10</sup> AHA; Trendwatch, April 2011.

<sup>11</sup> HRSA; Office of Rural Health Policy.

rights. These requirements are not a free-standing ethics standard, but rather are embedded in patient rights language, which is more generic in its contextual application.<sup>12</sup> The usual institutional response to this requirement is to establish an ethics committee structure through which patient rights concerns can be processed. In rural areas, these committees rarely have among their members persons experienced or trained in sorting out ethical controversies. Therefore most of the 60 rural hospitals in North Carolina are forced to resolve bioethical issues in patient care unassisted by informed ethics experts or knowledgeable committee members. Needs for ethics resources, including education for staff, assistance in structuring ethics committees, and consultation regarding ethical dilemmas, largely go unmet, a fact well documented even in the relatively thin body of literature that focuses on rural ethics.

The lack of ethics resources matters on many levels. Foremost, all patients, regardless of where they happen to be hospitalized, ought to be able to expect they will be cared for in an ethical manner; that is, in particular, having their personal autonomy respected. There are economic benefits tied to providing an ethical environment for patient care as well. Perhaps the most tangible is retention of experienced staff. Ethical conflicts are ubiquitous in healthcare and are a common cause of distress among caregivers, particularly among nurses who are present with the patient 24 hours a day. When moral distress is constantly fueled by dueling expectations, that is, believing one action is the right action but being required to take an opposite action, nurses suffer compounding psychological manifestations. A common scenario in which ethics conflicts occur is near the end of life. When the family refuses to allow a DNR order to be written for a dying patient despite the patient's prior request not to be subjected to

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<sup>12</sup> The Joint Commission, Hospital Standards Handbook, TJC (2011).

resuscitation. Moral distress can be defined as a conflict between a person's core value system and duties they are expected to perform. Moral distress came to a public view in an article in the *New York Times* published in 2009 which generated hundreds of on line responses from health care professionals and the public.<sup>13</sup> Moral distress has been discussed in nursing literature for some time as a predictor of how long nurses will stay in the field.<sup>14</sup> Nurses who report a frequent sense of being powerless to provide the type of care they believe the patient wanted or needed is a common cause of moral distress among these professionals. Power differentials in the physician-nurse relationship combined with a lack of knowledge or skill set to deal with ethical controversy, can result in bedside nurses feeling a sense of loss and failure to fulfill their duty to advocate for the patient. Over time this sense of loss drives nurses from the hospital and either out of the profession or to lower impact practices such as physicians' offices.<sup>15</sup> Loss of nursing staff has an immediate negative effect on hospital operations and patient care. First, the ratio of nurse providers to patients immediately drops until new staff can be recruited putting stress on remaining staff and reducing the amount of time a nurse is able to devote to bedside care. To control labor costs hospitals strive to provide adequate staff to patient ratios but at the same time attempt to maintain thin staffing margins to reduce overhead costs. Recruitment of professional staff in a rural area is more difficult as the pool of available nurses is small. Additionally, recruitment of experienced professional staff is both labor intensive and costly. For rural hospitals, labor costs account for the biggest proportion of budget growth and now represents an average of 54.8% of 2010 rural hospitals' expenses.<sup>16</sup>

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<sup>13</sup> Chen, P. (2005). When physicians and nurses can't do the right thing.

<sup>14</sup> Saver, C. (2009). Life and death scenarios lead to moral distress in nurses.

<sup>15</sup> Pendry, P. (2007). Moral distress: recognizing it to retain nurses.

<sup>16</sup> Broome, Sarah, January (2012)

Significant moral distress among professional caregivers may be an indication that the hospital's environment does not support a *just culture*. *Just culture*, a concept developed by engineer David Marx, seeks to find a middle ground between a blame-free culture in which no individual is held accountable, and an overly punitive culture, where individuals are blamed for all mistakes.<sup>17</sup> A just culture recognizes that competent people make mistakes and acknowledges that even competent professionals can develop 'normalized deviances' (generally accepted variations from written policy or procedure) that may contribute to error. A just culture however, has zero tolerance for reckless behaviors that result or could result in error or harm. Included in the concept of just culture is a top down expectation of mutual respect among all staff and intolerance of disruptive disrespectful behaviors. Patient safety has been tightly linked to an environment of ethical patient care. Recent studies reinforce that good communication between care givers is a major factor in reducing errors in health care.<sup>18</sup> Effective interdisciplinary communication occurs in an environment that supports a just and ethical institutional culture.

Sadly, the day is rapidly approaching when there will likely be no new community hospitals in the true sense of the term. Mega medical industries, some with an academic mission and others for-profit entities, have taken up the business of placing satellite facilities in rural locations which have been strategically determined to be useful in extending their market share. As satellites they are likely, at least in the beginning, to be a cut-and-paste of the urban mother ship, which would tend not to be inclusive of the local culture. The community hospital and the many benefits it brings to a rural locale may be a relic of past days when small towns were more self dependent for

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<sup>17</sup> Marx, D. 2007.

<sup>18</sup>Life Wings. <http://www.saferpatients.com/leadership/patient-safety-instructors.htm>; Life Wings.

goods and services. Klugman and Dalinis craft this statement to describe the sensitive nature of rural ethics: "Rural healthcare ethics is complex, subtle and multidimensional...and requires a sophisticated understanding of the rural context."<sup>19</sup> It is likely that leadership transplanted from the urban mother ship will not have an awareness of how healthcare in a rural culture differs from their experience in a metropolitan hospital. An ethics network could reach out to leadership of satellite hospitals with an offering of education to assist them in understanding and bridging the gap between urban and rural approaches resolution of ethical issues.

When undertaking a project such as this ethics network aimed at bolstering ethical competence of community hospital staff, all elements of rural culture must be carefully weighed, balanced and incorporated in a thoughtful development and service delivery plan. Viewing rural culture and the ethics of healthcare in a rural setting through this contextual lens will help inform how an effective local effort to provide ethics resources can be launched.

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<sup>19</sup>Klugman, C.M. & Dalinis, P.M.(2008)

### Chapter 3: North Carolina's Diverse Physical and Human Geography

The literature of early American history illustrates that a state's historical underpinnings are tied in part to both its geography and topography. So then are its cultural and social patterns. Whether the bioethics network project is to be a state wide effort or regionalized, these factors should be weighed and merged into a strategy for addressing ethics needs which may vary from region to region. Understanding cultural patterns and identifying subcultures inherent in regions of the state will inform the development of an effective infrastructure required to deliver the resources most appropriate for the region.

North Carolina is a predominately rural state which has a long history based in an agricultural economy. The drivers of North Carolinas economy are transitioning from manufacturing, mining, agriculture, and other labor-based industries to those which are knowledge-based, such as biotechnology and service related industries. The state, however, continues to maintain a strong agricultural sector, livestock products and crops each contributing about 50% of North Carolina's agricultural income.

In 2010 North Carolina's gross state product was approximately \$425 billion, ranking the state in the top 10 of all states in this product metric. However, the per capital income of the state's population, which in 2007 was about \$34,000, earns North Carolina a ranking of 36<sup>th</sup> among the 52 states and illustrates an interesting dichotomy to the production metric.<sup>20</sup>

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<sup>20</sup> North Carolina Department of Commerce (2011).

For many years tobacco was the primary crop grown in North Carolina. Tobacco now comprises about 40% of the crops industry while the amount of farm land being converted to grape acreage has more than doubled in the last decade. North Carolina ranks 9th in wine and grape production in the United States. According to the North Carolina Department of Commerce, the wine and grape industry generates an annual economic impact of \$1.28 billion and supports nearly 7,600 jobs.<sup>21</sup> The North Carolina Forestry Association reported the forestry sector, which includes lumber, furniture, wood products and paper as part of the states gross agricultural product, contributed approximately \$28 billion to the State's economy in 2007 and provided employment for some 80,000 workers.<sup>22</sup> Of historical note, North Carolinians came to be called "Tar Heels" in the pre civil war area when the state was preeminent in the pine, pulp, and pine tar market.

Jobs in manufacturing of textiles and furniture, once a major contributor to the economy has fallen off as production work has been sent off shore to reduce corporate costs. Many rural areas in North Carolina developed around textile and furniture factories which were the primary economic engines for these small towns. Out sourcing many of these jobs to low wage off shore markets has deeply affected those economic balances. Urban areas, on the other hand, magnet locales for banking, biotechnology, and other knowledge-based industries, have experienced rapid population and economic growth while many of the state's small towns have suffered from loss of jobs and population.<sup>23</sup>

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<sup>21</sup> North Carolina Department of Commerce (2011).

<sup>22</sup> NC Forestry Association. Annual Report (2007).

<sup>23</sup> [Netstate.com/economy/nc\\_economy.htm](http://Netstate.com/economy/nc_economy.htm).

North Carolina is the 28<sup>th</sup> largest state in America with a land mass of around 54,000 square miles, stretching across 560 miles from Tennessee to the Atlantic and 150 miles wide from Virginia and Tennessee to South Carolina and Georgia.<sup>24</sup> In 2011 NC's population was projected to be 9,656,401 making it the 10th most populous of the 50 United States.<sup>25</sup>

The eastern coast and coastal plain, occupy 45% of the state's land mass, the Piedmont region contains the middle 35%; and the Appalachian Mountains and foothills make up the remaining 20%. Encompassing a broad range of landscapes, these regional land variations stratify the state's climate, soils, plant life, as well as its historical and cultural heritage. Quite different social, political, and cultural characteristics distinguish the three regions. The state's metropolitan areas have a more liberal tendency, for example, while the rural piedmont, coastal and Appalachian regions remain strongly conservative.

In 1653, the North Carolina coast became the eighth of the first 13 colonies in America settled by the English.<sup>26</sup> Considered by some to be part of the southern 'low country' the coastal area has a largely seafaring and tourist economy though the inland landscapes of the region contribute to the state's agricultural product. Coastal fisheries are also a mainstay of coastal economy. Eastern North Carolina contains very few major urban centers and few areas of the region are experiencing economic growth. One exception is the coastal resort area's growth of real estate sales (Wilmington, for example). Another is Greenville and Pitt County which are both experiencing growth

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<sup>24</sup> [Netstate.com/states/almanac/nc\\_alma.html](http://Netstate.com/states/almanac/nc_alma.html).

<sup>25</sup> United States Census Bureau, July 1, 2001.

<sup>26</sup> <http://www.revolutionary-war.net/13-colonies.html>.

due the economic boost provided by East Carolina University and its associated medical facilities, including the fast growing East Carolina Heart Institute.

The Piedmont region of central North Carolina contains the state's most urbanized and densely populated areas. As North Carolina's economy shifts away from labor-based business to knowledge-based enterprises such as biotechnology, pharmaceuticals, banking and information technology, these industries have been drawn to the Piedmont region where goods, services, labor are abundant.

The Appalachian Region of western North Carolina is part of a nationally designated 205,000-square-mile land mass which follows the Appalachian Mountain range. It includes 29 North Carolina counties, all of West Virginia and parts of 12 other states. All but three of the 29 counties in the region are designated as rural areas. The economy of the Appalachian Region in North Carolina, historically heavily invested in forestry, mining and agriculture has in recent years diversified to include manufacturing, recreation, resort destinations and a growing service industry.<sup>27</sup> Tourism and land development for residential use accounts for the majority of the service industry. In the sparsely populated mountain regions, especially in North Carolina's southern mountains, ways of life have changed more gradually than in urban areas. Many communities, relatively isolated since the early history of the state, long remained self sufficient.

North Carolina is organized into 100 counties which fit into these three very diverse geographic regions. All but 15 counties in North Carolina are classified as rural.<sup>28</sup> North Carolina counties having a population density of no more than 250 people

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<sup>27</sup> Appalachian Regional Commission.

<sup>28</sup> NC Rural Economic Development Center data.

per square mile at the time of the 2000 U.S. Census were defined as rural. This definition of rural has been incorporated in legislation adopted by the N.C. General Assembly.<sup>29</sup> For the purposes of gathering population based statistical data, the Office of Management and Budget (OMB) has developed a set of definitions to describe areas of the country by the density of population in relationship with the degree of economic and social integrations within a core area. As defined by the OMB in 2003 a metropolitan statistical area (MSA) must have at least one urbanized area of 50,000 or more inhabitants. Micropolitan statistical area must have at least one urban cluster of at least 10,000 but less than 50,000 populations.<sup>30</sup> There are fifteen metropolitan statistical areas, and twenty six micropolitan statistical areas in North Carolina. These designations are used to capture population demographics of the state as they relate to urban, suburban, and rural areas. Population demographics of North Carolina are in general alignment with national data. Thirty two percent of the state's population occupies non-metropolitan areas whereas 16% of the total US population is rural. The poverty rate in non-metropolitan areas in NC is 4% higher than the US average. About 18% of North Carolinians are uninsured. North Carolina has a largely rural land mass and a predominantly rural population.<sup>31</sup>

### Cultural and Racial Diversity

In terms of its racial landscape, the state's population is predominately non-Hispanic Caucasians, whites comprising about 68% of the total population. Persons who describe themselves as African American or black make up 21%, and about 8% of the state's

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<sup>29</sup> NC Division of Health Services Regulations; NC DHSR, Office of Emergency Medical Services.

<sup>30</sup> OMB, <http://www.census.gov/population/www/estimates/metrodef.html>.

<sup>31</sup> NC Department of Commerce., 2011 data.

population is Hispanic.<sup>32</sup> Almost eighty-six percent of Western North Carolina's population is rural.<sup>33</sup> In her book, *APPALACHIA: A History of Mountains and People*, Spacek notes "More is known about Appalachia that is *untrue* than about any other region of the country". Emblematic of American cultural stereotypes, a persistent view of Appalachia is that it is home to moonshiners and hillbillies. On a Fox news segment broadcast to millions of Americans in 2009, commentator Bill O'Reilly characterized Appalachia as "...a lost cause and an area full of drunks." He referred to the area as a "culture of poverty," and said ..."There is a reason why some areas remain poor, generation after generation despite massive assistance." The Appalachian region has long been associated with and struggled with poverty, however, O'Reilly's unfortunate public comments were not based in factual data.

It could be said that when the demand for electricity exploded during the 19<sup>th</sup> century, lands rich in coal and the labor force that mined it were sacrificed for the sake of energy. Appalachia's coal mining industry provided the majority of work in western North Carolina during that time. Out-of-state industrialists who owned and operated the mines felt no great demand for facilitating or providing secondary industries or support services for the miners or their families. Infrastructure such as roads, water, and electricity were not demanded by the labor force, therefore were not prioritized so these needs went unmet. During the 1940s there were 450,000 jobs for men working the mines (Miners as a labor force are virtually all male). In 1960 this number dropped to 200,000 and in 2000 there were only about 100,000 mining jobs left in all of Appalachia. The nature of external industrial forces that fueled the economy of the mountains in

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<sup>32</sup> US Census data.

<sup>33</sup> North Carolina Appalachian Development Plan 2009-2012.

those days may have prevented or at least circumvented the development of a local civic culture that ultimately drives communities to grow and thrive. In spite of the many burdens that come of mountain living, or perhaps because of them, the people of Appalachia are a unique culture, independent and rich traditions of resiliency and community along with a strong sense of place that have helped them persevere through exceedingly difficult times. It would be fair to say that common ground among the people inhabiting the mountainous region includes a great love for the land and a deep commitment to the history it holds for them.

African Americans or non Hispanic Blacks are the largest minority population in North Carolina. Evidence of inclusion of Blacks in North Carolina culture can be identified in all regions of the state beginning in the early 1800s. During the pre-civil war period large plantations located in the coastal region employed vast numbers of Negro slaves as their primary labor force thus introducing African Blacks to the state. In the piedmont region during the 1820s the Salem Moravians played a role in Black history welcoming Blacks into their houses of worship. Blacks and whites were buried alongside one another in God's acre, the Moravian cemetery. When the Moravians finally succumbed to social pressure to at least recognize slavery, a separate Black church, the African Moravian Church, was built nearby. A few decades later, in the western part of the stat, George Vanderbilt commenced construction of Biltmore House. Though it no doubt produced abundant employment opportunities, this house must have been a *bête noir* to the local folk many of whom lacked even adequate shelter. The construction labor force also included a large number of Negro craftsmen not native to the mountains. When he undertook the Biltmore project in 1862 Vanderbilt commissioned a building to serve as a locale for social, cultural and religious activities of local African-

Americans. This landmark building has been restored and serves now as a cultural center for the preservation of the African American history of North Carolina. Blacks had a role in the State's military forces as far back as 1865 when a contingent of former slaves and free blacks, called the U.S. Colored Troops, famously engaged in battles as soldiers in the Union Army efforts to capture Fort Fisher in 1865 and were recognized for their bravery. Perhaps the most famous incident in the history of blacks in North Carolina occurred in 1960 when four local black college students sat down at a whites-only Woolworth's lunch counter in Greensboro. Though this was a small act of defiance and a peaceful protest the courage of these four young Black men became an important part of the civil rights movement that would eventually change American society forever.

The most significant change in cultural and racial diversity in North Carolina is the immigration of Hispanics into the state. Benchmarking recent population statistics with 2000 census data, Hispanics are the fastest growing minority population in the US and North Carolina is one of 16 states counting half a million Hispanics among their population.<sup>34</sup> In terms of heritage, people of Hispanic-Latino origin may be Mexican, Puerto Rican, Cuban, Salvadoran, Dominican, or of other Central or South American origin. The terms Hispanic and Latino are often used interchangeably, begging the question of which is culturally correct. A 2008 survey conducted by the Pew Hispanic Center found 36% of respondents preferred the term "Hispanic," 21% preferred the term "Latino" and the rest had no preference.<sup>35, 36</sup> For the purposes of this essay the term Hispanic will be used to include persons who identify themselves as Latino or Hispanic.

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<sup>34</sup> Silberman, P., Bazan-Manson, A., Purves, A. H. Odom, C. H., Et Al. (2003).

<sup>35</sup> Corbett, P. *New York Times*, June 9, 2009, Hispanic? Latino? Or What?

<sup>36</sup> Passel, J & Taylor, P. (2009). Who's Hispanic? Pew Hispanic Center/Pew Research Center.

Hispanic culture and its traditions are characteristically family centered. In this culture, family is intensely regarded and as a unit, functioning as the primary source of support and protection for members and very close friends. The term Hispanics use to describe their deep and commitment and loyalty to extended family is *'familisimo'*. In keeping with this cultural value, when a Hispanic patient arrives at the hospital he or she is likely to be accompanied by a contingent of family members who remain quietly but persistently present. Another important concept in the Latino culture is *respeto* (respect) which is grounded in the value placed on interpersonal relationships and has bearing on the health care relationship.<sup>37</sup> Hispanics place a high value on demonstrating respect in interactions with others. *Respeto* is the notion that persons are expected to defer to those who are in a position of authority because of age, gender, social position, title, economic status, etc. When manifest in a doctor-patient relationship, this cultural more requires deference to the physician, male or female, who is viewed as an authority figure. A requirement for deference may affect the patient's ability to make eye contact with the physician and could disallow questioning the physician's recommendations or even seeking more information from the physician. *Respeto* directs that older patients should be called *Señor* (Mr.) or *Señora* (Mrs.). This and other elements of culture affect the manner in which Hispanic people engage in a healthcare relationship. For the many small hospitals that serve Hispanic populations, the development of cultural competence continues to be a work in progress.

Valuing cultural diversity and demonstrating cultural competence is, in its essence, a fulfillment of the ethical duty of respect for persons and their right to autonomy. Nelson et al describe cultural ethical care as "...an effort to systematically

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<sup>37</sup> NC Latino Health, 2003; Cultural Factors & the health of north Carolina Latinos.

relate health care ethics to the cultural, ethnic, religious and social context in which ethics conflicts arise.<sup>38</sup> Incorporating the nuances of all the sub-cultures found in North Carolina should be a priority consideration in the development of programs through the bioethics network.

### North Carolina Hospitals

North Carolina's health care infrastructure has at its core the four large urban academic medical Centers, Duke University Hospital, Pitt County Memorial Hospital, University of North Carolina Hospitals and Wake Forest Baptist Medical Center. Together these medical facilities provide over 3000 patient beds. The academic centers are tertiary institutions which co-operate with other hospitals in the state, including rural community hospitals, to offer highly specialized health care services on a referral basis. In rural areas of North Carolina healthcare is primarily provided by local Community Hospitals. North Carolina has 122 acute care hospitals in 83 counties. Seventeen counties are not served by a local hospital. Sixty of the state's hospitals are considered rural hospitals.<sup>39</sup> The state's smallest hospital is Bertie Memorial Hospital located in Windsor. Bertie Memorial has only eight total hospital beds and operating rooms but offers an important service to its somewhat isolated local community.

According to a recent report from the AHA, there are 5795 registered hospitals in the US serving a population of 62 million. Registered hospitals include AHA member hospitals as well as nonmember hospitals including 'rurals'. Rural hospitals provide essential health care services to nearly 54 million people, including 9 million Medicare

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<sup>38</sup> Nelson, W et al. (2009). Handbook for Rural Health Care Ethics, Introduction: p.4

<sup>39</sup> RAC; states: NC.

beneficiaries. The Center for Rural Affairs, describes ten priority issues confronting rural hospitals<sup>40</sup>:

- rural economies are largely based on self-employment and small businesses (only a small percentage provide insurance coverage to workers)
- public health insurance plans (rural hospitals have a disproportionately high rate of patients insured by low paying public plans such as Medicare)
- stressed hospital delivery systems (low patient flow rates, an at risk population, and shrinking reimbursement for services)
- health care provider and work force shortages (Most HCPS areas are in rural areas)
- an aging population
- a sicker, more at risk population
- need for preventive care, health and wellness resources (typically provided by state run clinics, such as County Health Departments, few services beyond necessities such as immunizations, are provided)
- lack of mental health resources (common to most rural areas)
- increasing dependence upon technology (the healthcare industry as a whole is utilizing technology small rural hospitals cannot readily afford)
- effective emergency medical services (high level trauma services are only located in large urban hospitals; many rural areas lack a emergency response infrastructure and plan)

Each of these issues contributes heavily to the pressure rural hospitals face in continuing to provide critical services to their constituencies. In order to stay afloat, small rural

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<sup>40</sup> Bailey, J. (2009). The top 10 rural issues for health care reform; Center for Rural Affairs.

hospitals tend to delay capital projects needed to keep up with advances in medical and information technology, additions to or improvement of their facilities, or to engage other actions which would help attract health care professionals as well as patients. The importance of rural hospitals in the grand scheme of health care in America shouldn't be underestimated. In recognition of the unique needs of rural hospital, The AHA established a Section for Small or Rural Hospitals (SSRH). SSRH aims to represent the unique needs of its 1600 members in areas such as public policy making.<sup>41</sup> For purposes of Section membership the AHA requires that a hospital meet at least one of these criteria: have 100 or fewer beds, 4000 or fewer admissions, or be located outside a Metropolitan Statistical Area. The SSRH provides an important national networking forum for rural hospitals across the country.

In sum, it is clear that small community and rural hospitals in North Carolina play a critical role in providing healthcare for a large percentage of the population which has a diverse cultural heritage. In the context of their rural locations and typically small size, these hospitals face a host of challenges which are different from urban institutions, including shortages of health care professionals, limited ability to capitalize growth and advancement of technologies, and a paucity of available resources to maintain or enhance skills of their staff and leadership. It is well known that racial and ethnic health disparities are linked to poorer health outcomes and lower quality care. Among the explanations for this is that language and cultural disunity can have a significant impact on patients and staff when not addressed by health care organizations.

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<sup>41</sup> AHA (2012).

Geographically large and culturally diverse, North Carolina offers many challenges when one contemplates development of a road map towards establishing an ethics network. Viewing this challenge through within the context of demographic and geographic data, it makes sense to recognize the cumulative aspects of regionalism by structuring the network logistically with regional partners geographically located who can deploy services to network members in all regions.

## Chapter 4. A Review of Rural Ethics Networks

America's settlement history was founded in the pioneering, rugged individualism of those who forged new pathways into an unknown country. Sub-stations within rural geographies, where goods and services were made accessible to surrounding settlements, grew into towns. Those towns having geographic characteristics which facilitated commerce grew into cities. Over a century many these cities of early America have grown into large urban areas where populations are dense and multicultural, and where services and goods are abundant. Other rural settlements grew slowly or disappeared as their thin populations migrated to other locales where they were more likely to prosper. Today over 23% of the US population occupies rural areas and 75% of US land mass is classified as rural.<sup>42</sup>

Basic characteristics of rural areas discussed above (isolation, limited access to goods and services, community centricity, and others) create special challenges for rural communities and their health care providers. A study of critical access hospitals (CAH) done by Nelson, et al, in 2010 found that only 60% had ethics committees or an ethics consultation program in their hospitals.<sup>43</sup> He noted that hospitals in the most rural of locations were less likely to have identified ethics committees. The problem of limited access to ethics resources and education has been addressed in some areas of the country by the creation of multi-institutional ethics networks. Nelson supports this concept saying "Rural ethics committees can be linked to statewide ethics networks, which can foster useful support for often isolated rural committees. .... (and) can

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<sup>42</sup> Multiple sources including RAC.

<sup>43</sup> Nelson, W.A. et al (2010). The presence of ethics committees in critical access hospitals.

enhance rural ethics committee members' knowledge."<sup>44</sup> Networks serve as a vehicle to link rural health care providers with a variety of ethics resources which can render guidance in the management of moral and ethical problems encountered in rural healthcare delivery. Ethics networks operate across the US in geographically diverse areas. Networks may have a statewide or a regional agenda and vary widely in the formality of their infrastructure. They may exist independently in rural areas where ethics resources are limited or may reside within academic centers which provide access to abundant resources, including faculty and graduate students. A frequently articulated goal of ethics networks represented in the literature is to facilitate communication among network member-providers creating an awareness of shared common ground and mutual support in addressing clinical ethics. Common ground shared by rural community hospitals is the notion that their sphere of day to day ethics is unique and far different from that of urban America. Ethics Networks listed on the Internet include those listed below.

- Rural Bioethics Project of Montana
- West Virginia Network of Ethics Committees (WVNEC)
- Medical Ethics Resource Network of Michigan
- Vermont Ethics Network (VTN)
- Bioethics Network of Ohio (BENO)
- Maryland Healthcare Ethics Committee Network ((MHECN)
- Ocean state Ethics Network – off line now (OCEN)
- Midwest Ethics Committee Network (MECN)
- The Florida Bioethics Network (FBN)

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<sup>44</sup> Nelson, W.A. (2007) Ethics Programs in small rural hospitals.

- Arizona Bioethics Network

Some networks have been durable over a number of years and others have gone dormant. A review of the startup history of these networks suggests a network's ability to thrive is based on several critical characteristics predictive of long-term success. Ultimately the key feature of a functional, enduring rural ethics network is having a catalogue of services relevant to its targeted membership. Effective identification of the prospective network users' needs and their desire for resources is fundamental. A comprehensive needs assessment informs the development of beneficial resources tailored to meet these needs within the rural context of a small community. Though it seems a simple mental construct, surprisingly, network developers sometimes under appreciate this step. When one teases apart how networks typically come into existence the root cause of this oversight is more apparent. Networks are likely to have been envisioned and driven into existence by individuals or small groups of people in academic centers or medical institutions who recognize a need for networking and have the skills and resources necessary to develop the project. This skill set is most likely to be found among well educated and well connected urban academicians or health professionals. Therein is found a significant risk factor that can mitigate against success. Because these experts are typically urban academicians and professionals in large and formal institutions or universities, their experiential framework and knowledge base are in the narrative of urban ethics. The genre of urban ethics does not fit the framework of rural America. When this reality goes unrecognized, these experts may attempt to apply a framework of urban ethics whose key elements don't resonate with rural America.

A factor identified to be common in failed ethics networks is coming out of the box with an agenda that is inattentive to the ethos of rural health care and its providers. Another is initiating an agenda that is large, assertive and overly ambitious. It can be argued that inaugurating a network with a modest agenda developed in consensus with representatives from rural health care systems in the region is the most likely to be successful. A comparison between the West Virginia Network and the Ocean State Ethics Network illustrates these characteristics of success.

The West Virginia Network of Ethics Committees (WVNEC) models the maintenance of a successful network. WVNEC resides within an academic setting, The Center of Health, Ethics & Law at the University of West Virginia (UWV), and is associated with the professional schools of Nursing, Medicine, Dentistry and Pharmacy at the Robert C. Byrd Health Sciences Center. Perhaps a portion of its success can be attributed to the fact that UWV is located a decidedly rural state where both the University and the Center share a focused mission to serve a rural market, including a rural student population. Actually, the entire state is considered to be part of the nationally designated Appalachian Region. WVNEC is guided by an advisory board whose eight members represent eight different non-academic health care institutions. Five of the eight members are nurses and there are no faculty or physician members. Focus on the rural nature of its service area is reflected in the mission statement of the WVNEC:

“The West Virginia Network of Ethics Committees assists hospitals, nursing homes, hospices, and home health care agencies to strengthen ethics committees; provides education regarding ethical and legal issues in health care to promote ethically

sound decision making; and helps patients and families to make their end-of-life wishes known. ”<sup>45</sup>

Its website, [www.wvnec.org](http://www.wvnec.org), describes membership services and benefits including a complete toolkit for ethics committees available on line. Among WVNEC’s other services are:

- Noon hour audio conferences addressing pressing issues for ethics committees at a member-discounted rates;
- E-newsletters and a list serve communicating state and national developments in ethical and legal issues pertaining to patient care;
- Quarterly newsletters containing articles on current topics in medical ethics in West Virginia and throughout the country;
- Discounted registration for all WVNEC educational events;
- Telephone consultation regarding ethical issues in patient care;
- Information on implementing West Virginia health law;
- Assistance in drafting institutional policies on ethics-related issues

WVNEC, which came into being as a collaborative ethics interest group in about 1988, will host its 24<sup>th</sup> annual conference in 2012. The Network boasts a membership of 71 institutions and 14 individuals<sup>46</sup>. Members represent a wide range of healthcare entities and professionals including retirement communities, nursing homes, convalescent centers, hospices and hospitals, nurses and physicians. In 2008 WVNEC had an all-time high roster of 86 institutional members. Since then the Network has experienced a slow

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<sup>45</sup> [www.wvnec.org](http://www.wvnec.org).

<sup>46</sup> WVNEC annual business meeting minutes. (2010).

decline in membership which they attribute to financial challenges facing healthcare, especially in rural areas. WVNEC receives administrative and program support from UWV. The Network's institutional membership fee structure is based on gross revenue of member hospitals and is quite modest. However, our own Piedmont Bioethics Network experience of declining key memberships offers a cautionary tale in this regard. Even small dollar membership fees for non-critical functions will be sacrificed to achieve the financial goal of budget cuts in an institution faced with unacceptable margins. To be safe, membership dues should be viewed only as an adjunct to other fully committed funding. Using its middle of the road institutional membership fee, \$250, and based on 70 members, WVNEC's revenue from membership is about \$18,000. In addition to this revenue source, the Network gains about \$7000 of annual revenue from audio conferences and portable educational programs. However, the WVNEC reports a net loss from annual on-site symposia.

Several messages are embedded in the details of this budget information. First, the most successful revenue producing education programs are those providing distance learning in the form of audio conferencing, CD or other electronic media. Out of pocket costs and staffing constraints, particularly in thinly staffed rural institutions, pose significant barriers for members to attend on-site conferences. A set of programs called the WVNEC Noon Conference Series features interactive discussion of common ethical issues that are cross cultural and endemic in all types of health care institutions. Topics include "The Medical Power of Attorney Representative isirate: What's going on?", "Is Incapacity a Permanent Thing?", "Treating the Refusing Patient with a Psychiatric Disorder, "DNR from a Nursing Perspective and "I just want a 'little' CPR." In addition WVNEC provides a set of practical, skill building tools for use in managing ethics issues.

These materials are not urban centric, nor are they rural-centric; rather they provide practical information and guidance that can be used in institutions that provide all levels of care, including palliative and hospice care.<sup>47</sup> Marketing of useful tools, along with a culturally competent perspective about rural ethics and stable funding are major contributors to WVNEC's success.

The Ocean State Ethics Network (OSEN) demonstrates quite a different ethics network model. A telling piece of OSEN's context is this bit of history. "...a breakfast meeting took place at the Brown University Faculty Club on February 6, 2003. The goal was to establish a regional ethics network."<sup>48</sup> OSEN quickly grew to 60 members though it is unclear from its literature what diversity that membership included. In 2006-2007 OSEN's board of directors included ten members, four of whom were Brown University Faculty, four were faculty from other academic medical programs, and two were other persons who may have been community members. OSEN offered the majority of its programs as two hour conferences which appear to have been held in the evenings from 530 to 730 on the Brown University Campus. All but one of OSEN's educational offerings were attendee based on-site conferences. Educational sessions featured current topics regarding common and perplexing issues in patient care, such as "Court-Appointed Guardians: Strangers at the bedside?", "Living with Grief: Ethical Dilemmas at the End of Life", "Ethics Consultation: Nuts and Bolts", and "Barriers to Advance Directives". Other conference topics were more scholarly in nature: "Time to Pull the Plug on Substituted Judgment?", "Suffering & Justice: Topics from the ASBH Meeting", "Dissent on Informed Consent", and "Medicine in the Marketplace: Commerce or Compassion?". These academic topics would no doubt fully engage students and

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<sup>47</sup> WVNEC web site.

<sup>48</sup> OSEN web site; hx.

faculty in the Bioethics program at Wake Forest University but may not have been practical in terms of meeting the needs and expectations of its network members. OSEN appears to have envisioned their network through an academic lens and sought a more scholarly approach using faculty from Brown and other prestigious universities to educate its members about bioethics. Begun in 2003 with a hearty and strong inauguration, OSEN is now "off-line" while the WVNEC continues to be very active in its network. What are the differences?

The most critical element of success in the construction of a rural bioethics network is that bioethics is viewed not through the traditional lens of urban America but rather in the context of rural culture. The Montana Rural Ethics Project (University of Montana) published combined findings from a research series conducted between 1997 and 2002 that speaks to the importance of cultural relevance.<sup>49</sup> In this series of eight surveys targeting nurses, physicians and hospital administrators, Cook and Hoas found that rural healthcare providers wanted ethics resources that enhanced their abilities to successfully engage in ethics discourse with physicians and patients, that supported competent patient care and that included contextual values relative to rural culture and norms.<sup>50</sup> The respondents were most interested in interactive resources and programs that would provide new skills for use in negotiating bedside ethical issues they routinely experienced. Specifically these participants rejected literature, ethics case based text books or self study materials which in their view failed to present material in the context of rural healthcare.

Committed, long term funding is another key predictor of success. Several of the networks noted above were originally funded by grants. Vermont Ethics Network, for

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<sup>49</sup> National Rural Bioethics Project, University of Montana.

<sup>50</sup> Cook, A.F. & Guttmanova, K. (2005).

example, was funded by a grant from Robert Wood Johnson foundation in 1986 and has since gained steady financial support from a variety of other sources. Other networks rely on financial support from affiliated universities, and some count on support from membership combined with income from education products sold via its network. Membership dues make an important contribution to a network's success. However, in rural systems this is an unreliable source of funding over time. Most networks provide low cost options for individual memberships thus opening membership to interested persons without a formal institutional affiliation. Individual membership is a minor contributor to the network's bottom line; however, these unaffiliated but interested and motivated members tend to contribute importantly to the network's multidisciplinary/multicultural dialogue.

Sustaining success in the long term may require dedicated staff to manage the business of the network. Though member benefits and services offered by the network ultimately determine the need for staffing, business of the network is typically based on opportunities for at least frequent if not daily access. Volunteer staff are challenged to isolate adequate time and space to perform daily network functions. Part time staff is a better option but may still result in a reduced rate of responsiveness to network business. Communications, especially in the early phases of network building, suffer when this occurs. The Arizona Ethics Network (AET) inaugurated in the early 1990s lacked a formal structure and "...quietly faded away after a number of years into what its former volunteer director characterized as "organizational dormancy".<sup>51</sup> AET was resurrected in 2010 funded by a 2 year grant and now faces demise again having not yet indentified a funding source to carry on.

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<sup>51</sup> Arizona Bioethics Network; [azbioethicsnetwork.org](http://azbioethicsnetwork.org).

In summary, predictors of the long term success of a network include a stable funding source, at least one committed staff and skill in assessing the needs of membership and providing access to resources that can address those needs in a culturally relevant manner. By comparing the infrastructure of WVNEC, which boasts long term success and that of OCEN which did not, we can see, at least in this model, an illustration of predictors of success.

Clearly, recognition of and attention to the essential purpose of the network is the fundamental requirement for success. Within the membership of its advisory board, The West Virginia network has utilized partners with 'boots on the ground' experience to design and implement its programs. For all the value added though the application of academic expertise, the town and gown metaphor is appropriately applied when considering grass-roots engagements in rural areas. What works is to clearly define a primary target audience, to understand the learning needs of that group, and then to build programs designed to specifically and in a culturally competent manner to address identified needs. While an argument can be made for the value of real time interactive discourse in ethics education, clearly the most basic need is that it must be widely accessible. This benefit becomes more valuable as organizations become leaner.

My own twelve year experience with the Piedmont Bioethics Network (PBN) provides a case study on the challenges of sustaining a not for profit bioethics network. PBN was formed in 1998 by a coalition of hospitals, a mix of urban and non urban institutions, located in the Triad region of North Carolina. More correctly, the network was formed by a coalition of *bioethics champions* from these hospitals. Bylaws were written and it was incorporated as a not for profit 501c3 organization in 1999.

PBN's mission was to assist area health care providers offer high quality ethics services to their patients. In its mission statement, PBN stated that it existed to:

- facilitate networking among area health care providers and other interested persons
- provide resources for ethics education to health care providers
- provide resources for consultation on difficult cases
- provide resources for institutional policy development'
- promote reflection on and response to ethical issues in health care.<sup>52</sup>

PBN endeavored to host annual area-wide educational events, a quarterly Board meeting, a speaker's bureau, and consultation services. These services were not so much focused on a rural agenda as they were on the practical application of bioethics principles to every day ethical dilemmas, a need expressed by the broad membership. The champions of PBN were practicing 'ethicists' who on a day to day basis provided counsel regarding ethical concerns to staff, faculty and patients in their respective institutions. Though the PBN agenda did not specifically seek a rural community, these real-life ethics experts brought the value of practical ethics to those it sought to serve in the region.

The Network held its inaugural conference, "Healthcare Ethics for the 21<sup>st</sup> Century" in the fall of 1999. Though attendance expectations for a first meeting were realized, 53 registrants, costs exceeded registration income. PBN made up the difference with from its budget. The second annual conference, "The New Portable DNR as An Advance in Patient's Rights: Medical, Ethical, Legal and Practical Considerations", brought in double the number of attendees, but once again costs exceeded registration

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<sup>52</sup> Introducing THE PIEDMONT BIOETHICS NETWORK (Informational flyer).

income and PBN made up the difference from its educational budget. Though changes were made to reduce expenses, the PBN's annual conferences consistently failed to reach the minimal goal of breaking even. Financial challenges associated with the production of its key activity, the annual conference, were an ominous early sign for an organization that lacked sponsorship.

Indeed, the first challenge PBN faced several years into its tenure was that funding was inadequate for its agenda and even funds derived from membership fees became unstable. Funds were used to stage annual meetings and to provide meals for quarterly meeting attendees. Most attendees paid their travel to meetings from personal funds. All officers of the network were volunteers. Leadership was dependent upon availability of the officers. PBN had elected to have a physician president who in all cases was a busy practitioner.

After several years, PBN recognized a pressing need to have a paid part time administrative coordinator, a job description was developed, and a person was selected to assume that role. This cost, though modest, took a significant portion of PBN's budget. The quality of network business communications, annual meeting activities, and data management significantly improved. However, financial reserve remained marginal and PBN was challenged to make good on promises of resources and benefits to membership.

Despite having a great enthusiasm for bioethics and a strong commitment to assist other care providers in the region to apply bioethics in practice, competing responsibilities, travel requirements, dwindling income and constraints on time began to take its toll among the members. In 2010, after much heartfelt and frank discussion, it was decided by the membership that Piedmont Bioethics Network could no longer be

sustained without a committed sponsor and infrastructure. PBN relinquished its 501c3 status and became inactive. Many of PBN's members have continued to network, sharing information news and offering assistance to one another from that time on.

PBN offers a cautionary tale to others who endeavor to reach out to the community in this way. It takes more than good and committed people with the best of intentions to sustain a network seeking to provide a broad reach of ethics resources in this economic era. The reality is that it takes money to create and maintain a bioethics network infrastructure that will be successful in reaching out into the community.

This writer's experience with PBN, as a board member, and later as an administrator reinforces the learnings gleaned from research of other ethics networks examined above in two ways:

- A focus on *members* expressed need for theory and practical application of bioethics resources is the linchpin. The membership's perceived value and not the academician's sense of what are priorities must prevail.
- Physical conferences, though they create a substantial forum for networking and relationship building, are not practical for meeting the needs of network membership. In the PBN experience travel proved to become increasingly difficult over time, both literally and figuratively.

Two key take-home messages are loud and clear:

- Resources must be brought to the membership instead of attempting to bring the membership to resources.
- Stable administrative and financial support is critical to the effective deployment and maintenance of a good bioethics network.

Based on demographic, social, and cultural features of rural North Carolina, it is clear that of the networks reviewed, the West Virginia model is most likely to have success in our region. WVNEC is centered in U WV presumably because it is a small state and because its funding largely comes from U WV. Because North Carolina is a much larger state and there is a willingness on the part of several universities to provide some level of support, a single center-based network with satellite academic partners who will participate in on-site visits may be a useful strategy. A foundation of truly collaborative effort between community, community institutions, and academia will be required to fuel the engine of this endeavor.

## Chapter 5. Assessment of Ethics Resource Needs in N.C.'s Rural Hospitals

As discussed in previous chapters, rural populations, and rural hospitals have characteristics unique to the local culture within which they dwell. This uniqueness requires that tools used to assess their education and resource needs be developed within that rural context and the information gained from such an assessment be viewed in the context of rural culture. If information gathered is to ultimately be productive of actionable goals, the self-defined needs and preferences of the responders must be effectively captured. These goals could best be accomplished by persons trained to develop survey instruments. For the purposes of this essay, however, three *de novo* tools were developed using straightforward questions to sample general opinions of rural hospital staff members. The rubric was consistent with typical survey response choices to which they would have previously been exposed

The assessment tools were then deployed to determine resource needs of hospital staff and those of the hospital's Ethics Committee (EC).<sup>53</sup> (See Appendix for assessment tools) Each instrument is a multi question document designed to capture a sense of the hospital's ethics environment as seen by the respondent. Response choices ranged from (1) low rate of agreement to (5) a high rate of agreement. The goal of this broad range of options was to capture the respondents' degree of resolve for their choice of a positive or negative response to the queries. The instrument included a request for documentation of the respondent's professional category (RN etc.) and specialty or work area. Respondent's name and contact information was an optional field. A write-in opportunity of 'other' allowed further explanation or comments. The instrument was first tested in Hospital "A".

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<sup>53</sup> Assessment tools are found in Appendix.

Hospital "A" has a well established ethics vehicle in the form of its ethics committee (EC) which has been operational for many years. In addition to leadership and staff from pastoral care, nursing, specialty areas (such as obstetrics) three physicians attended the site visit meeting and were integral in the discussion of network project opportunities. These physicians represented key areas including the emergency department and obstetrics. The CEO attended meetings where this writer was present to discuss the network project and, as well, he volunteered to participate in the ethics survey. Approval for Hospital A to participate in this network thesis project was achieved in a two step process in a month's time. The project was first introduced to the CEO by the champion, the Director of Hospital A's Pastoral Care Department. After the CEO agreed to participation, the ethics committee was asked to join in the leadership commitment. Having a mature ethics infrastructure and embedded ethics champions was highly contributory to the hospital's engagement in the network project. Data retrieved from the survey supports this belief.

The survey instrument was delivered to the hospital staff utilizing an internal software program (*NetLearning*). Members of the ethics committee received the instrument as a handout during a committee meeting at which this author presented the thesis project and entertained discussion of project components. Members were asked to return the completed survey via internal mail.

Three hundred and Fifteen (315) responses were received from the staff survey. Of them 44.8% were from nursing, 19% were from nurse aids, 3.8% were from leadership, and 26.3% were from "other". Some surveys did not provide a professional title or category. The optional category of 'other' included representatives of professional groups such as social workers and case managers. Hospital A elected to

conduct a physician survey after the data from this initial assessment was reviewed. Of all respondents, 84.8% worked in the acute care hospital and 14.9 % in the hospital's nursing center. Approximately 60% of the respondents provided their name. Respondents used an average time of 5 minutes to complete the survey.

The response to all questions posed in the prototype instrument was most frequently (3), average. Two statements were observed to have the greatest aggregate rate of below average or low agreement responses and thus scored the lowest rate of above average or high rates of agreement. The statements were "Patients and family members routinely access the ethics committee for guidance in decision making," and "We routinely have bioethics consultants who act as a resource to our staff and physicians and who respond to our educational needs." These responses did not come as a surprise and documented a clear opportunity for network engagement.

Perhaps the most unexpected response was a high rate of positive agreement with this statement: "I am confident of my ability to identify and respond to ethical conflicts in patient care." Nearly 95% of all respondents rated themselves average or better, with 51% of those claiming that they had above average or high skill levels in ethical interaction involving patients. All respondents agreed at a level of average to high confidence that "Our hospital has an ethics committee which provides a resource for staff, physicians, patients, and families when serious conflicts arise (97%). Another area of strength was that respondents overwhelmingly agreed (97.8%) to an average or high degree that their hospital had policies to guide the ethical care of patients.

In summary, this assessment indicated the staff was quite aware of an ethics presence in the hospital, agreed that they had policies and internal resources available to them, and revealed the staff had an unusually high rate of self confidence in their

ability to handle ethics issues in the clinical setting. The staff perceived a need for patients and families to have a greater degree of awareness about the availability of ethics resources. An important finding that illustrates the value of the network project was the staff's desire for additional educational resources and more access to ethics experts.

All three assessment tools were later evaluated in context of value the responses generated to inform the network project. Upon review it was noted that data collected was more generic nature than might have arisen from thoughtful individual responses, therefore the instrument was revised in several ways. First, the 'other' option was not found to have provided quality information. To enable a more open-ended response, 'other' was changed to 'explain or comment'. The challenge of receiving 'write in' options rests in the availability of time required for respondents' thoughts to be captured. Further testing of 'explain/comment' opportunities in the survey will be done to determine if this section is useful in a broad target audience or if it can be best utilized in focus groups where committed time is available for completing the tool. The instrument did not capture the staff's perception of areas of greatest need for ethics resources. This was a significant missed opportunity to solicit information from an audience that cannot be re-approached in the near future. In most circumstances a survey project is 'a one trick pony'. Survey fatigue becomes a factor when a large target audience, such as an entire nursing staff, has been asked to take the time and effort to complete an assessment. This suggests that at least an immediate re-survey is not likely to elicit a positive response. Because this information is crucial in terms of specific resources a hospital may require, the instrument will be revised to better capture such data and deployed again in a future staff engagement.

The EC in hospital A was provided with the prototype EC instrument. Data obtained from the survey of committee members was consistent with the results obtained from the general staff survey but included more write in responses. For example, it was noted by one member that budget constraints had prevented adequate continuing education for EC members. Responses of the EC survey indicated that the committee sees itself as having an open, positive and interactive dynamic, being right-sized, and well represented by various disciplines. Members felt they had limited to no access to consultants and low to below average orientation to their ethics committee role. The instrument design, again, did not effectively solicit as thoughtful a set of responses as was hoped based on the generic nature of those received. Because these individuals are a focused group that has a stake in the results of the survey, they are likely to be open another go with the revised tool. The EC assessment instrument has been revised to provoke a more deeply thoughtful engagement. It will provide members the opportunity to indicate that, while their committee is active and successful, more could be done to improve the hospital's culture of pro-active ethical patient care.

In contrast to Hospital A, the ethics committee (EC) at Hospital "B" does not appear to enjoy a well oiled infrastructure supported by institutional leadership. Hospital B, though it has had an EC for several years, seeks still to clarify its mission. This hospital's engagement in the network project has been hindered by a multi step process of approval up a chain of command that ultimately includes the Board of Directors. The CEO of Hospital B attended the site meeting for a short time, coming in late and leaving early. The CEO did not engage fully in discussion and during his brief appearance he occupied a physical posture that distanced him literally and figuratively from the proceedings. Hospital B felt that assessment tools developed for the purposes of the

network project were too complicated for use at the current stage of their ethics committee's development therefore the hospital planned to develop "an extremely basic" tool for use in an initial survey. At the time of this writing, Hospital B has not yet executed delivery of an assessment instrument to its staff. Requests for assistance in writing of a mission statement and re-structuring of committee activities made to this writer were fulfilled. Hospital B seeks guidance in re-engineering the ethics course of its institution. Discussion with the EC spokesman has not provided objective data about leadership buy-in. However, based on the experience gained during interactions with Hospital B leadership, commitment appears to be marginal. A real time discussion or written query to the EC as an effort to gain insight about leadership support or the lack thereof would be an interesting exercise but in the current climate would likely be futile in terms of gathering meaningful data. Anecdotal information at hand does not permit an objective evaluation of factors which obstruct the energy for ethics engagement at Hospital B. Members of the committee present during the first site visit meeting appeared to be uninformed about the agenda and were unclear about expectations for their participation in the discussion. Yet, after a slow start, they became engaged in an animated conversation with this writer and each other about opportunities a network could provide to them and the hospital.

Experience gained in hospitals A and B, in conjunction with a long history of professional engagement with rural/community hospitals, funds the belief that leadership support is critically important for a hospital to develop ethics competencies. Leadership commitment includes making thoughtful appointments to ethics committee membership that result in improved committee function. For a culture of ethics to prevail, executive leadership must also assume responsibility for effective inclusion of

ethical patient care and corporate practices. The CEO is often the hinge point of a successful engagement in community hospitals. Experience in rural and communities hospitals demonstrates that access to executive leadership is relatively unobstructed, unlike the typically insulated leadership stratosphere of a large academic medical center. To make effective use of encounters with executive leadership, such as CEOs, one must be prepared with an offer of relevant information and a request for action. There has been little written in the literature about barriers to CEO access and leadership involvement in the development of an ethics culture and this should be explored in future field research. A detailed study of contrasts between well functioning hospital ethics committees and those that struggle would contribute valuable data to compose theories of development of those hospitals that have yet to find their ethics grounding.

A third instrument was crafted for use in doing an unannounced survey of five regional community and rural hospitals. Directors of pastoral care departments or known contacts within in the hospitals were sent an email letter describing the thesis project and soliciting their input via an attached survey tool. Recipients were invited to delegate the completion of the survey to another person within their institution should they so choose. Seven letters and surveys were sent and 5 completed surveys were received from these hospitals. All 5 hospitals reported having ethics committees. Of the 5, 3 meet quarterly, 1 meets every other month, and one meets as necessary. Three of the 5 indicated the EC was rarely or sometimes active in ethics matters related to patient care. Two do not have an ethics policy regarding care at the end of life, 2 have a policy, and 1 has a policy under development. All 5 reported that their ethics committee receives education on topics in ethics at least annually. Of the 5 hospitals, 4 indicated nurses rarely receive ethics education. Only one of the 5 indicated they did not have

access to an ethics consultant. The other four reported they occasionally have access or that they have access to a university based ethics consultant. Two of the 5 hospitals reported the culture of their hospitals were highly inclusive of ethical care of patients. Three reported a moderate rate of cultural commitment. Three hospitals indicated their staff and physicians were only moderately aware of the ethics committee and its resources; one reported a high awareness, and one reported not well aware. All 5 hospitals indicated they were interested in obtaining continuing education in ethics. Four of the five responded to this questions with a desire for resources, "if we had an ethics network, we would want it to..." In summary, each of the responses of this very small sample indicated at least several areas of need for ethics assistance. This data is consistent with the finding of large groups of surveys done by the National Rural Ethics Projects at the University of Montana. These data support the value that could be offered by a rural ethics network.

While rural ethics as a topic has been discussed in the literature for some time, the subject of how rural hospitals actually manage institutional ethics has yet to be fully explored. Factors that contribute to institutional ethics culture, such as leadership commitment, staff and faculty knowledge and skills, continuing education resources and psycho-social and spiritual infrastructure could all be investigated in a well planned multi-institutional study. Hospitals can and do incur significant costs related to ethics conflicts, likewise a subject that has not been well described in the literature. Objective data associating ethical conflicts with costs incurred in legal fees, staff attrition, and loss of market share could provide influential literature to support institutional investment in ethics resources.

As noted in the introductory chapter, advances in medical technology such as mechanical ventilation and treatment options including the ability to maintain cardiac viability during extended surgical rescue operations has contributed immensely to the impending explosion of aging of baby boomers that are already affecting hospital acuity rates. We know that in rural populations the elderly, as a group, are not well insured and that they have greater than average health risks.<sup>54</sup> These patients are beginning to arrive at the doors of rural hospitals in greater numbers than ever before, impinging upon the hospitals already scarce resources. The influx of frail elderly patients posed to be approaching end of life issues will increase the staff's burden of ethical conflict. An ethics network, anticipating these changes, could build a progressive series of informative case based teaching scenarios and make this available to membership using various methodologies. A weekly case could be posted, for example, with a question based format seeking interaction from users and through this interactive discussion, provide guidance on conflict resolution.

What has been most useful in terms of coming to an understanding of the culture and resource needs of a hospital are personal visits which have been organized to include both an ethics committee meeting presentation and other meetings with individuals who have a stake in developing a culture of ethics. Face to face meetings very often result in development of a seedling relationship which can be nourished along to produce a deeper insight of the hospital's strengths and weaknesses. These relationships mature into contacts which serve to assist the network/hospital partnership to navigate towards achievement of their mutual goals.

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<sup>54</sup> Rural Economic Development Center.

The narrative of healthcare ethics is in stories maintained with varying degrees of secrecy. After all, these are tales of private human frailty and suffering. Ethical concerns and patient events involving ethics conflicts are topics not openly discussed in a hospital setting and generally not discussed outside of a hospital's 'membership'. The development of relationships of trust would be necessary to create a safe place for open dialogue with hospital professionals about these challenges. It can be anticipated that an unfolding of openness to such discussion would occur in stages as trust grew between hospital and network participants, beginning with stories that are safe and easy for the staff to share with an outsider. Discussion of *uncomplicated* challenges staff face when a patient is at the end of life, for example, could be low hanging fruit; so common among professional care givers as to be 'safe' stories. As the easy stories are shared with a receptive and non-judgmental consultant, the troubling events, secrets, will eventually find a voice.

## Chapter 6. Analysis and Recommendations

In a review of the literature from 1966-2004, Nelson, Lushcov, et al found 55 substantive publications that addressed rural healthcare ethics. However, only 13% of these publications featured original research.<sup>55</sup> Today, the body of literature that exists is much richer, including publications from many disciplines and scholarly fields. Authors from public health, medicine, nursing, and social work arenas have engaged in productive research and informative reviews of data that has lead to the conclusions<sup>1</sup>discussed in this essay. The following characteristics of rural populations have been described by these authors:

- Rural populations represent a unique American culture whose values include self reliance and independence which both influence healthcare decision making
- Shortages of health care professionals are endemic to rural areas
- Rural populations are at increased health risks at all ages
- Rural populations are more likely to be under or uninsured
- Rural populations have limited access to health care services
- Rural hospitals face extraordinary economic stressors and have limited access to capital funding
- Health care professionals in rural areas lack access to peer support
- Rural healthcare providers have significant needs for ethics education and support resources.

While all these characteristics are not individually unique to rural populations, when compiled into one 'rural' demographic data set they become a critical mass that earns

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<sup>55</sup> Nelson, WA et al. (2006). Rural health care ethics: Is there a literature?

rural residents vulnerable population status. One could also argue that rural healthcare providers constitute a vulnerable *professional* population. Numerous hazards, such as unique ethics conflicts, lack of resources (including continuing education), and poor rural economies, create hardships for health care professionals practicing in rural areas.<sup>56</sup> Nelson, et al, discussed the importance of recognizing these and other factors representative of the rural environment as a context that engenders unique ethical conflicts.<sup>57</sup>

An analysis of rural people and rural areas in North Carolina substantiates the need for ethics resources. The 60 rural and community hospitals in North Carolina are scattered over the entire geography of the state. Though rural cultures vary somewhat by region, bedrock characteristics described above are common to all. Ethics resource needs commonly cited in the literature include focused, culturally appropriate education, easy access to resources and education, access to electronic consultative assistance, peer networking, on site ethics consultants, and links to ethics web sites, and ethics news. Anderson-Shaw and Glover discuss the value that a statewide ethics network can provide.<sup>58</sup> Building on their experience and the experiences of others collected above, a sensible and effective strategy for development of the North Carolina Ethics Network can be constructed.

Rural community hospitals play a crucial role in providing health care to over 72 million Americans. Unlike large urban referral-based medical centers, the community hospital is about local people in its area of small service. Baernholdt notes that the hallmark of large urban hospitals is highly specialized high tech care in contrast with

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<sup>56</sup> Purtilo, RB, (2009) The ethical life of rural health care professionals.

<sup>57</sup> Nelson, WA, et al. (2007). A proposed rural healthcare ethics agenda.

<sup>58</sup> Anderson-Shaw, L and Glover, JJ. (2009) Developing rural ethics networks.

rural hospitals whose hallmark is individualized, patient and family centered care.<sup>59</sup> In her research on rural hospital quality, Baernholdt found that nurses from rural areas made clear a distinction that their patients were not sent to large urban hospitals because the care was better but rather to provide them access to advanced treatments unavailable in their rural hospitals. Baernholdt also discovered something unexpected. Achievement of patient satisfaction, not reaching metric goals established for quality measures, was how rural nurses identified themselves. Ensuring the patient felt cared for was the first priority of both nurse administrators and staff nurses. In context of the rural community healthcare this is very logical as a good hospital experience paves the way for the patient, his or her extended family, friends and neighbors to use the hospital's services! This behavior may also demonstrate the hospital's top down, bottom up commitment to personalized care, thus to quality, which creates fertile ground for proposing resources aimed at helping them improve ethical care of patients.

#### What is the Network's mission?

The first question that must be asked and answered when considering development of an ethics network is "what will be its mission?" Mission can be defined as *an important assignment carried out for political, religious, or commercial purposes*, or as *a body of persons sent to conduct negotiations or establish relations with a foreign country*. Further down on the list is the 'charge' definition, *...business with which such a body of persons is charged.'* To create awareness of the mission as more than simply a charge to do business, I submit that all these definitions ought to be considered when crafting a network mission statement. Many options exist for ways a network might respond to ethics needs of rural hospitals expressed above. Based on the literature,

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<sup>59</sup> Baernholdt, M, Jennings, BM, et al. (2010). What does quality care mean to nurses in rural hospitals?

research in the field, and clinical experience, goals of the network should include providing members with education about basic ethics concepts and how they apply in a rural healthcare setting.<sup>60</sup> Other resources added to the staff and EC members 'wish list' include occasional site visits from experienced ethicists, consultation regarding policy development, assistance deliberating clinical scenarios, skills building, and mentorship. I propose below a draft mission statement which will serve as a framework to found discussion about services a network will provide members and infrastructure that will be required to deliver on promised services.

"The mission of the NCBN (North Carolina Bioethics Network) is to serve its members by facilitating dissemination of ethics knowledge and ethics conflict resolution skills through education, coaching, mentoring, consultative services, and by maintaining a web based forum for identification and exploration of ethical issues in rural community based health care.

Infrastructure required to assure successful delivery of promises the network makes to its members can be constructed on the good bones of an envisioned mission. Sectioning components of the mission statement helps to organize planning. The first goal is to define what is meant by 'network' in the context of this project. This proposal has the network based in an academic center such as Wake Forest's Center for Bioethics, Health & Society. The network would draw funding from its academic sponsor(s), from grants, and from membership dues. As discussed above, membership dues cannot be expected to sustain a network but can help to offset some expenses. Interest expressed by other academic

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<sup>60</sup> Cook AF. Et al (2005) From here to there.

institutions, including University of North Carolina, may indicate funding support would be forthcoming from those participating.

The first component of the network is its communication mission. Successful negotiation of ethics terrain is first and foremost based in effective communication. This can be rough going for rural health providers caught in power differentials between, for example, nurses and physicians, or nurses and administration. Armed with a clear understanding of basic ethics concepts (such as the right of personal autonomy), ability to recognize when circumstances reach a threshold of ethical conflict, and confidence to engage in communication with other providers to resolve these, the geography of stiff ethics challenges can be navigated. Strengthening abilities of both staff and institutional practice to successfully intersect health care delivery and ethical care of hospital patients clears at least a path to just culture.

The 'network' is a virtual entity. Its utility as a railway for network-member interactions will require development of a web site. While much of networking communication will be electronic, in person discussion and on site interactions will make ethics partnership dialogue much richer. Staffing needs will depend upon how much human-to-human service will be offered to network members. This proposal envisions a network director/manager who would coordinate the network's business and be available to respond to membership requests on a day-to-day basis. Other manager responsibilities would include member hospital site visits to assist with ethics committee work, to perform education programs, to conduct research functions, or to provide other consultative or supportive services. If the network is staffed, it will require a physical work area location, equipment including a computer, printer, land or cell telephone, internet connectivity, office supplies,

storage and other business related paraphernalia. This could be an institutional or off-site location.

The second component of the networks offering is education. Fulfillment of the education mission will require access to trained ethics consultants and educators, to a references library, to a provider number for continuing professional education credits, and seed money for inaugural conferences. Learning modules may be constructed, borrowed or purchased. The manager would plan and coordinate on line and on-site educational offerings including, for example, an annual rural ethics conference. There are good examples of educational programs, teaching tools and materials available through other ethics networks such as WVNEC. The Dartmouth Rural Health Care Ethics Manual for Trainers, freely available via the internet, contains a wealth of information, including case studies.

Coaching and consultative services comprise the third component of the network's mission. These services can be fulfilled in many different ways, one of which is through is development of a mentoring group. McCoy suggests that mentoring is among the most useful forms of professional training and development.<sup>61</sup> Mentoring also facilitates relationship building which ultimately would strengthen the networks interactive communication. From the standpoint of efficiency, mentoring is an available and inexpensive way to build staff confidence in their ethics competencies. Within the context of this project as a network for rural hospitals, not all mentoring must be or should be done by academic ethics experts. Seasoned persons skilled and experienced in managing ethics conflict in rural settings will be among members of the network. These individuals should be

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<sup>61</sup> McCoy, C. (2009). Professional development in rural nursing.

identified and developed as a peer support resource group for 'friending' by other rural network members. Having this peer group as part of its infrastructure could stimulate a dynamic of intellectual curiosity among rural network members. On line and telephone consultation will fill a majority of consultative functions. However, nothing can approximate the value of in-person on site visits from the network's team of experts. While the network must not posture itself as having the capacity to respond to urgent needs, an 'on-call' structure of trained individuals could be made available to help address sensitive member requests. Infrastructures necessary to fulfill a mentoring promise will include insuring member's access to a network manager, an ethics educator, or an ethics content expert, whether based in the community or academia. Budget consideration should include travel expenses, access to vehicles, and insurance coverage for site visitors.

After assuring that its deliverables are culturally relevant, effective and appropriate, the next most important element necessary for successful operation of a network is to identify a stable financial commitment. Without financial stability, the network will be challenged to consistently provide promised resources to its members. Experience of other networks, including our own piedmont bioethics network, demonstrates that most small hospitals are unable to make a long-term commitment to funding of a network or its activities.

Development of a long-term financial strategy and identification of a long term funding commitment must precede seeking engagement with prospective member hospitals. A business plan should include annualized costs for services the network will offer its membership (including educational programs), for infrastructure needs noted above such as staffing, maintenance of a web site, a

work place, equipment necessary to conduct network business, purchase of training materials, access to a reference library, and miscellaneous expenses. Funding opportunities from local, state and federal grants programs and a strategy and timeline for accomplishing grant applications should be identified and included in both the network's short and long term strategic plans. Local foundations, state medical, nursing, and health care administration organizations, and rural healthcare resources can be considered as sources of grants. National organizations such as the Hastings center and professional ethics organizations may offer grants for the project or certain aspects of its services. Grants should be written to provide multiyear funding which is renewable after an inaugural contract period.

#### Next steps

Assessment of all rural hospitals in North Carolina was not within the scope of this essay but should be done to develop a deeper appreciation for inclusive needs of the state's rural hospitals. Gaining a perspective of the reception this network proposal would receive would be necessary as an early step forward. To further elucidate a culturally sensitive statewide education strategy this expanded evaluation of non-metropolitan hospitals could be mapped out by regional academic partners matching ethics resources housed in academic centers to meet regional needs for ethics activities. A longer look at how ethics conflicts impact hospital budgets would be very informative. Another area of useful research would be to comparison patient safety data in hospitals identified as having a robust ethics culture versus those that do not.

If the network project goes forward, an important early step would be to engage staff and leadership of rural hospitals in network planning. A steering group made up of rural hospital representatives would help to assure authenticity in program development.

A series of conversational meetings could be initiated with rural providers to begin building a networks partnership. Using a template agenda would help to insure that critical information is collection from each of the groups convened.

Recommendations:

It may be concluded from this essay that health care providers serving rural communities are a vulnerable professional group. One element of this vulnerability is the reality of diminishing financial support hospitals can offer the staff for continuing education (CE) and professional development. Ethics is even more likely to fall lower on the list of CE topics as priorities for clinical expertise will take precedence. Academia has before it an opportunity to engage a very important community mission: to reach out with ethics knowledge and ethics conflict resolution skills through education, coaching, mentoring, and consultative services in rural community hospitals. In partnering with these hospitals the network reaches virtually all members of their communities. The Center for Bioethics, Health and Society should take up this challenge, engaging faculty, students and other interested parties to develop a map to put ethics on the road in rural North Carolina.

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Appendix A.

**Institutional Ethics Environment and Needs Assessment Survey**

1. My role in the hospital is: \_\_\_\_\_
2. Our hospital has an ethics committee. YES \_\_\_\_\_ NO \_\_\_\_\_
3. If yes, our ethics committee meets: annually \_\_\_\_\_ quarterly \_\_\_\_\_ monthly \_\_\_\_\_ weekly \_\_\_\_\_ as needed \_\_\_\_\_ other \_\_\_\_\_.
4. The ethics committee in our hospital is active in ethics matters related to patient care: Very active \_\_\_ Active \_\_\_ sometimes active \_\_\_ rarely active \_\_\_\_\_ Other \_\_\_\_\_
5. Members of the ethics committees are educated on topics in ethics: Annually \_\_\_\_\_ Quarterly \_\_\_\_\_ monthly \_\_\_\_\_ rarely \_\_\_\_\_ other: \_\_\_\_\_
6. Our hospital has a an ethics policy regarding end of life care: Yes \_\_\_ No \_\_\_
7. If yes, our policy is: Very helpful \_\_\_\_\_ helpful \_\_\_\_\_ not very helpful \_\_\_\_\_ Other \_\_\_\_\_
8. Our hospital experiences controversy in ethical care of patients: More than once a week \_\_\_\_\_ weekly \_\_\_\_\_ monthly \_\_\_\_\_ rarely \_\_\_\_\_ other \_\_\_\_\_
9. The nursing staff in our hospital have training in ethical issues related to patient care: Annually \_\_\_\_\_ quarterly \_\_\_\_\_ monthly \_\_\_\_\_ rarely \_\_\_\_\_ Other \_\_\_\_\_
10. The culture of our hospital is inclusive of ethical care of patients: Highly \_\_\_\_\_ Moderately \_\_\_\_\_ Somewhat \_\_\_\_\_ Other \_\_\_\_\_
11. The makeup and size of our ethics committee allows multidisciplinary discussion. Yes \_\_\_\_\_ No \_\_\_\_\_ Other \_\_\_\_\_
12. Our hospital culture encourages and promotes bedside ethics consultation: Strongly \_\_\_\_\_ moderately \_\_\_\_\_ rarely \_\_\_\_\_ other \_\_\_\_\_
13. Our ethics committee has developed appropriate policies to guide ethical care of patients: Very useful \_\_\_ moderately useful \_\_\_\_\_ not very useful \_\_\_\_\_ other \_\_\_\_\_
14. Our hospital has access to bioethics consultants who act as a resource to our committees and respond to our educational needs: Regularly \_\_\_\_\_ annually \_\_\_\_\_ quarterly \_\_\_\_\_ Other \_\_\_\_\_

15. In our hospital writing and approving policies regarding ethical issues such as futile care and DNR is done by: Leadership \_\_\_\_\_ ethics committee \_\_\_\_\_ physicians \_\_\_\_\_ nursing \_\_\_\_\_ chaplains \_\_\_\_\_ other \_\_\_\_\_

16. Physicians and staff access the ethics committee for guidance regarding ethical conflicts: Every day \_\_\_\_\_ every week \_\_\_\_\_ several times a month \_\_\_\_\_ rarely \_\_\_\_\_ Other \_\_\_\_\_

17. The staff and physicians in our hospital are aware of ethics committee and our resources: well aware \_\_\_\_\_ moderately aware \_\_\_\_\_ not well aware \_\_\_\_\_ Other \_\_\_\_\_

18. Patients and family members access the ethics committee for guidance in decision making: frequently \_\_\_\_\_ occasionally \_\_\_\_\_ rarely \_\_\_\_\_ other \_\_\_\_\_

19. Our hospital's greatest needs for assistance regarding ethics is: staff education/training \_\_\_\_\_ consultation \_\_\_\_\_ policy writing \_\_\_\_\_ end of life decision making \_\_\_\_\_ physician education \_\_\_\_\_ Leadership education \_\_\_\_\_ Other \_\_\_\_\_

20. If your hospital/staff is interested in continuing education in the area of ethics, what format would work best for you? ( scale of 1-5; choose #1 for highest priority and #5 for least important)  
On site trained consultants \_\_\_\_\_ web based programs \_\_\_\_\_ annual conferences in a central location \_\_\_\_\_ CEUs \_\_\_\_\_ On line networking \_\_\_\_\_ ability to ask questions of experts and receive answers \_\_\_\_\_ on site physician education \_\_\_\_\_ Newsletter \_\_\_\_\_ access to breaking news \_\_\_\_\_ an educational series covering key topics available on line \_\_\_\_\_ Other \_\_\_\_\_

21. If we had a local ethics network we would want it to : \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Additional Comments: \_\_\_\_\_  
\_\_\_\_\_

Questions?: \_\_\_\_\_  
\_\_\_\_\_

Optional: Name \_\_\_\_\_ /contact email: \_\_\_\_\_

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Appendix B

**Ethics Committee Assessment Tool**

There is an active plan for providing orientation to new members of the committee. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

I would say that communication dynamics among the ethics committee members is open and positive. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

The makeup and size of our ethics committee facilitates multidisciplinary views and discussion. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Could be more diverse \_\_\_\_ Explain/comments \_\_\_\_\_

Cases are reviewed at committee meetings and ad hoc bedside consultation is encouraged and promoted. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

I believe our ethics committee has developed appropriate policies to guide ethical care of patients. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

We use external bioethics consultants on site as a resource to the ethics committee and to assist in meeting our educational needs Agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

Continuing ethics education is provided adequately for our committee members, for our hospitals physicians and staff. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

Our ethics committee includes community representation. agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

Our hospital has a well developed process for writing and approving policies regarding ethical issues such as DNR. Agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

The role of the ethics committee has been effectively promoted within our hospital. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

Hospital leadership actively supports the work and value of the ethics committee. Strongly agree \_\_\_\_ agree \_\_\_\_ don't agree \_\_\_\_ Explain/comments \_\_\_\_\_

In our hospital physicians and staff routinely access the ethics committee for guidance regarding ethical concerns. Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_  
Explain/comments \_\_\_\_\_

In our hospital patients and/or family members routinely access the ethics committee for guidance in decision making. Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_ Explain/comments \_\_\_\_\_

Our hospital experiences ethical challenges in patient care: Daily \_\_\_\_\_ weekly \_\_\_\_\_ monthly \_\_\_\_\_ rarely \_\_\_\_\_ Explain/comments \_\_\_\_\_  
\_\_\_\_\_

At our hospital the ethical concerns most frequently encountered are:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

If our hospital was part of a multi-hospital ethics network I would use it to \_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Additional Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Questions for survey team? \_\_\_\_\_  
\_\_\_\_\_

(Optional)  
Name: \_\_\_\_\_  
My role in the hospital is: \_\_\_\_\_  
Hospital: \_\_\_\_\_  
Contact information: \_\_\_\_\_

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Appendix C.

**Ethics Assessment Tool for Nursing**

Our hospital has an ethics committee which provides a resource for staff, physicians, patients and families when serious ethical concerns arise. Yes \_\_\_ No \_\_\_  
Explain/Comments \_\_\_\_\_

Methods for accessing the ethics committee are clear to nurses.  
Very clear \_\_\_\_\_ somewhat clear \_\_\_\_\_ Not very clear \_\_\_\_\_  
Comments \_\_\_\_\_

Managers, physicians and hospital administration support nursing staff referring questions or problems to the ethics committee. Strongly supportive \_\_\_ supportive \_\_\_  
not strongly supportive \_\_\_ Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

Ad hoc bedside consultation regarding ethical concerns in patient care is encouraged and promoted. Highly encouraged \_\_\_ encouraged \_\_\_  
Not encouraged \_\_\_ Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

Our hospital has policies that provide effective guidance regarding ethical care of patients Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_  
Explain/Comments \_\_\_\_\_

Our hospital routinely engages bioethics consultants as a resource to our staff and physicians. Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_  
Comments \_\_\_\_\_

Continuing education on topics in ethics is provided for our hospital's staff.  
Frequently provided \_\_\_ infrequently provided \_\_\_ rarely provided \_\_\_  
Comments \_\_\_\_\_

The staff receives institutional support for ethical decision making in patient care.  
Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_  
Comments \_\_\_\_\_

At our hospital patient care issues regarding ethical concerns occur:  
Daily \_\_\_ weekly \_\_\_ every month \_\_\_ rarely \_\_\_ Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

I am confident of my ability to identify ethical concerns in patient care.  
Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_ Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

I am confident of my ability to respond effectively to ethical concerns in patient care.  
Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_  
Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

Patients and family members access the ethics committee for guidance in decision making. Strongly agree \_\_\_\_\_ agree \_\_\_\_\_ don't agree \_\_\_\_\_  
Explain/Comments \_\_\_\_\_  
\_\_\_\_\_

In our hospital the most common ethical problems arise in the these areas:  
(On a scale from 1 to 5: use **1 for most frequent** and **5 for rare**)

Reproductive health/OB \_\_\_\_\_ End of Life \_\_\_\_\_ Newborn care \_\_\_\_\_  
Charity care \_\_\_\_\_ Mechanical life support \_\_\_\_\_ DNR \_\_\_\_\_  
Health Care Power of Attorney \_\_\_\_\_ Who is the decision maker? \_\_\_\_\_  
Feeding tubes \_\_\_\_\_ Right to refuse treatment \_\_\_\_\_ Language/cultural barriers \_\_\_\_\_  
disagreements about patient's rights \_\_\_\_\_ allowing a natural death \_\_\_\_\_  
Discharging patients \_\_\_\_\_ Other/Comments \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

As a nurse dealing with ethical patient care, my area of greatest need for support is: \_\_\_\_\_  
\_\_\_\_\_

Other comments. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Ethics topics of interest to me \_\_\_\_\_  
\_\_\_\_\_

Name (Optional):

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## Curriculum Vitae

M. Lisa Hammon

Home Address:  
1001 Dalton Road  
Lewisville, NC. 27023  
Work Telephone: 336-716-2061  
Fax: 336-716-6415  
Email: [lihammon@wakehealth.edu](mailto:lihammon@wakehealth.edu)

### Experience:

Administrative (Executive Director or Associate Director) 18 years  
RN advanced practice (faculty, program manager, service coordinator) 15 years  
Staff RN (Surgical ICU & specialty peds) 4 years

### Employment:

Wake Forest Baptist Medical Center

2009-Present Associate Director – Risk and Insurance Management

Responsibility for institutional risk management  
Review clinical cases for claims and litigation  
Director of clinical risk management functions  
Clinical services strategy for risk control  
Clinical consultation services for WFBMC faculty and staff  
Clinical staff of RNs and Risk Management Investigators  
Sentinel event process management  
Compliance with regulatory requirements related to patient events (TJC and CMS, etc)  
Budgeting for Department 576  
Performance review and supervision of Legal Nurse Consultant, Prevention Managers (3), and Risk Management investigators (7)  
Strategic program development  
Facilities development to accommodate staff

2006–2008 Coordinator Endoscopy/ERCP Services

Inaugurated new role for management of ERCP and GI Endoscopy Service  
Developed new strategies for management of referral services

2001-2006 Coordinator, Oncology Outreach Services

### Brief Summary of Duties:

Initiating, planning, implementing, and managing CCCWFU community hospital cancer center affiliations  
Development and implementation of operational strategic plans  
Development and implementation of marketing strategies

- Development of fee based affiliation agreements with outside hospitals
- Development and maintenance of effective communication networks
- Planning and coordinating Outreach Advisory Committee
- Overseeing operational issues related to outreach practices and affiliation sites
- Planning, coordinating and conducting annual strategic planning retreats for affiliated hospitals
- Developing and managing Outreach Department budget
- Developing and publishing Outreach Resource Manual

January 1, 2000 – March 23, 2001 Assistant Executive Director, Carolina Donor Services (CDS) organ and tissue recovery program. Winston-Salem, Raleigh, Durham. CDS is a non-profit organ and tissue recovery providing Clinical and educational services to 103 hospitals in 79 North Carolina counties. (Carolina LifeCare merged with Carolina Organ Procurement Agency in January of 2000 to form Carolina Donor Services.)

#### Brief Summary of Duties:

- Development and implementation of strategic plan for merger transition
- Supervision of development and marketing of name change
- Administration of clinical services
- Direction of public and professional education services
- Direction of donor family bereavement program
- Direction of volunteer program and public relations
- Business planning for merger and expansion projects
- Budget development and administration
- Staff recruitment, training, and management
- Supervision of management staff
- Supervision of development of strategic marketing plan
- Supervision of design, remodeling, and furnishing clinical office space in Raleigh
- Providing continuity of organizational leadership
- 1989-1999 Executive Director, Carolina LifeCare, WFBMC. (A non- profit organ and tissue recovery organization services hospitals a 23 county area)

#### Brief Summary of Duties:

- Development of liaison relationships and affiliation agreements with community hospitals
- Development of new logo and marketing materials
- Administration of clinical services, public and professional education, public relations,
- Development and administration of departmental budget
- Development of donor family care programs
- Development of volunteer program
- Development of standards of care and operating policies & procedures
- Development and implementation of strategic planning
- Maintaining compliance with state and federal regulators
- Grant writing and administration of grants
- Recruitment and supervision of management staff
- Identification, design, supervision of building and furnishing of new offices
- Supervision of development of strategic marketing plan

Creating and supervising VOCL, Volunteers for Carolina LifeCare  
Acting as organization's spokesperson  
Development and management of speakers bureau  
Development and production of public and professional educational materials

February 1989 – October 1990 Director of Education and Hospital Development, Louisiana Organ Procurement Agency, Metairie, Louisiana. The Louisiana Organ Procurement Agency is a non-profit organ recovery program providing clinical services and professional education to all hospitals in the state of Louisiana

.Brief Summary of Duties:

Development and management of professional education services and public education activities  
Public relations and development of local media relationships  
Development of logo and marketing materials  
Establishment and implementation of hospital liaison relationship procedures  
Management of hospital and public education services  
Negotiation of relationships with hospitals throughout the state  
Development Donor Resource Manual for area hospitals  
Development and production of public and professional educational materials  
Solicitation and coordination of speaking engagements for professional and public education  
Budget development and administration  
Acting as spokesperson for the organization

1986- 1989 Director of Education. LifeLink of Southwest Florida, (Organ and Tissue Recovery Program), Ft. Myers, Fla.

Brief Summary of Duties:

Negotiated and established affiliation agreements with area hospitals  
Developed operational policy and procedure  
Solicited and coordinated speaking engagements for professional and public education  
Developed relationships with local media to achieve increased visibility for OPO  
Organized, produced, and participated in professional education workshops  
Organized and produced physician educational programs  
Interacted with local physicians to facilitate donation process  
Negotiated affiliation agreements with uncommitted hospitals

Other Work Experience:

1986 -1988 Faculty, Nursing Department, Division of Allied Health, Edison Community College, Ft. Myers, Florida. Instructed and evaluated senior students in ICU rotations and labs and first year students in nursing skills labs.

1985 – 1996 Office Manager and Surgical Assistant, Periodontal Practice, Ft. Myers Florida. Supervised building and interior design of offices. Developed patient record

keeping billing, and scheduling systems, supervised staff, supervised office practices. First Assistant in hospital cases).

1981-1984 Pediatric Transplant Coordinator, Department of Surgery, Shands Hospital, University of Florida, Gainesville, Florida. Managed pre and post transplant education for pediatric transplant candidates and their families. Coordinated, facilitated, and summarized pre transplant evaluations of recipients and living donor candidates. Coordinated transplant admissions. Provided immediate and long-term post transplant education and follow up. Wrote pediatric transplant education booklet.

1980-1981 Director of Renal Services, University of Florida, Shands Hospital, Gainesville, Florida. Administrative and budgetary responsibility for adult and pediatric acute, chronic and satellite dialysis units. Managed clinical activities and staffing through Nursing Managers in each unit.

Nurse Director, Pediatric Hemodialysis Dialysis Unit, University, of Florida, Shands Hospital. Administration and management of acute and chronic pediatric dialysis facility providing services to patients two to three shifts Monday through Saturday and as needed on an emergency basis. Managed nursing and technical staff.

1977–1978 Staff Nurse, Acute/Chronic Pediatric Hemodialysis Unit, University of Florida, Shands Hospital. Provided direct hemodialysis care to pediatric patients.

1976-1977 Staff Nurse, Surgical Intensive Care Unit University of Florida, Shands Hospital. Provided intensive nursing care to patients admitted by neurosurgery, trauma, cardiothoracic surgery, orthopedics, and other surgical services.

#### EDUCATION:

BSN University of Florida  
MA-Bioethics (currently enrolled; graduation date May 2012)

Bachelors of Science in Nursing  
Post graduate course in Nursing  
University of Florida, Gainesville, Florida

#### PROFESSIONAL LICENSURE AND CERTIFICATION:

Registered Nurse, Florida, #82802-2  
Registered Nurse, Louisiana, #63440  
Registered Nurse, North Carolina, #114820

Certified Procurement/Preservation Coordinator American Board of Transplant Coordinators. CPTC #141, 1988 – 2002

#### COMMUNITY ACTIVITIES:

Board Of Directors & Executive Committee, N.C. Triad Affiliate Of The Susan G. Komen Breast Cancer Foundation  
Grants Committee – 2002-2005  
Chair Grants Committee – 2005 To Present  
Faculty, Medicine As A Profession; Wake Forest University, Bowman Gray School Of Medicine, 1998 - 2004  
Ethics Committee, Wake Forest University Baptist Medical Center, 1993-Present  
Chair, Education & Projects Subcommittee, 1995 - 2010  
Steering Committee, Community Partnership For End Of Life Care, A Partnership Funded By The Duke Endowment, Winston-Salem, 2000 –2009  
Habitat for Humanity – BirdFest Annual Fund Raiser Steering Committee – 1998-2006  
Sub committee Chair, Auction checkout and auction management  
Contributing artist, Bird Fest , 1999 - 2009  
Leadership Circle, United Way of Winston Salem (2000-2012)  
Board of Directors, Piedmont Biomedical Ethics Network, Highpoint, North Carolina, 1999 – 2006  
Executive Director – 2001-2006

areas of Special interest:

Ethics  
Death and dying  
Palliative care  
Mentoring  
Networking to develop partnering relationships  
Staff development  
Program development  
Resource/marketing materials development

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