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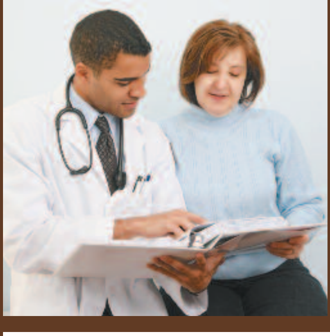

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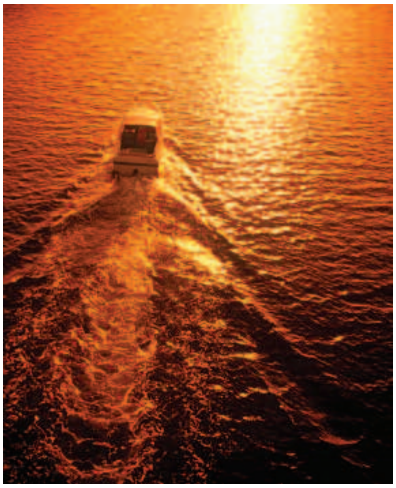



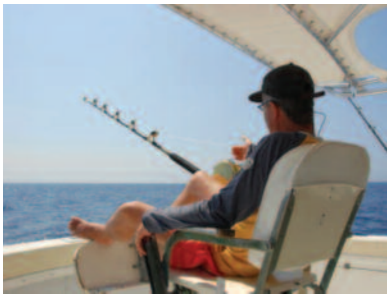
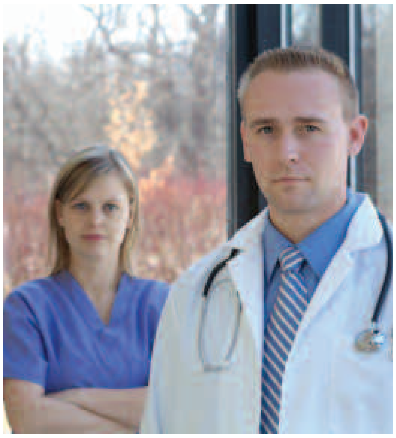


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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Connie Hawkins
Children's Advocate

As the parent of a young son with significant learning, speech, and language disabilities, Johnson City, Tennessee native Connie Hawkins knew first-hand about the challenges of navigating the "special education maze." Her son Michael was one of the first students with disabilities to attend Davidson Elementary School, and Ms. Hawkins learned very early that the team approach was the best way to support her son and his educators. She recognized that she needed knowledge and skills to be Michael's best advocate. She also recognized that there were many other parents who needed those things as well.

Ms. Hawkins's passion and commitment for improving the life and education of own child led her to team up with another passionate parent, Frank Graziadei of Charlotte, and Dr. Richard White, a special education professor at UNCC. Together they conceptualized and established the Exceptional Children's Assistance Center (ECAC) a private nonprofit parent organization. Then named the Exceptional Children's Advocacy Center, ECAC began as an all-volunteer organization that served as the Parent Advisory Board for the Charlotte—Mecklenburg School System. By 1983, the board received its first Parent Training and Information (PTI) grant from the US Department of Education (DOE), Office of Special Education Programs (OSEP) and began serving nine North Carolina counties. In the late 1980s, with continued funding from OSEP, the program began serving the entire state.

As the executive director of ECAC, Ms. Hawkins's vision for a full-service parent center has seen the organization expand far beyond the boundaries of disability to include all children. As challenges or opportunities for growth present themselves, the first question Ms. Hawkins and ECAC's Board of Directors ask is "what is best for North Carolina's children?" With four offices geographically dispersed throughout the state and nearly 50 staff members, ECAC's programs serve children from birth to age 26. These offices responded to more than 50,000 requests for information last year from parents, families, educators, and other professionals. All services are provided to parents and families at no cost.

ECAC is not only home to on of the nation's oldest federally funded Parent Training and Information Centers, it is also home to multiple projects including the NC Title 1 Parent Information and Resource Center (PIRC), the NC Family to Family Health Information Center, and the Region 2 Parent Technical Assistance Center (PTAC) which provides technical assistance parent centers in eight other states and the District of Columbia. Under Ms. Hawkins's leadership, ECAC is the only Parent Center in the nation to have the combination of all four of these major federally funded projects. ECAC has a strong collaborative relationship with the North Carolina Department of Public Schools and works tirelessly with public school leaders to improve educational outcomes for all students.

Ms. Hawkins has developed a national and statewide reputation as a devoted advocate for the educational rights for students with and without disabilities. She is a well-known speaker and workshop presenter on topics related to special education, school reform, children with disabilities and special health care

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needs and their families, and parent/professional collaboration, and was the original co-author of *Parents Together*, a manual for North Carolina parents of children with special needs. Ms. Hawkins has a degree in journalism from Queens College and continues her education through graduate courses in nonprofit management, special education, and law.

Ms. Hawkins currently sits on the advisory boards of the National Early Childhood Technical Assistance Center (NECTAC), the National Secondary Transition Technical Assistance Center (NSTTAC), the National Center on Education Outcomes (NCEO), and the National Center on Learning Disabilities. In North Carolina she actively participates in the NC DPI Superintendent's Parent Advisory Committee and the NC Special Needs Federation, and was heavily involved in the NC Continuous Improvement Monitoring Process. Additionally, she is a charter member of the NC School Improvement Commission and also participated in the NC Legislative Study Commission for Children with Special Needs.

I met Connie Hawkins in 1984 during an ECAC parent training workshop conducted at my daughter's school. When I had questions or concerns about her educational program, Connie and ECAC were there with the answers, support and encouragement our family needed to be effective partners with our daughter's teachers and other school staff members.

If you ever meet Connie Hawkins you won’t forget her and she won’t forget you. With her red hair, infectious laugh, and understanding Irish blue eyes, parents instantly know they are not alone in their journey and professionals know there is no one more committed to improving outcomes for children. During a recent evaluation of ECAC’s services one parent said, “If it hadn’t been for the support, encouragement, and knowledge I received from Connie Hawkins, my son would have never graduated from high school… and he’s going to college this fall!” Ms. Hawkins deeply believes that parents are experts about their children and, when supported with knowledge and skills, they can become their child's best and most effective advocate.

And Michael? Michael is a grown man now and teaches English to college students in China—a far cry from the little boy who had few language skills for so many years.

Contributed by
Mary LaCorte, assistant director of the Exceptional Children’s Assistance Center,
and the director of ECAC’s PTI Project.

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PEER-REVIEWED ARTICLE

Racial/Ethnic Differences in Quality of Care for North Carolina Medicaid Recipients

C. Annette DuBard, MD, MPH; Angie Yow, RN; Susan Bostrom, RN; Emad Attiah, MSc; Brad Griffith, MBA; William Lawrence, MD

Abstract

Background: *National health care quality measures suggest that racial and ethnic minority populations receive inferior quality of care compared to whites across many health services. As the largest insurer of low-income and minority populations in the United States, Medicaid has an important opportunity to identify and address health care disparities.*

Methods: *Using 2006 Healthcare Effectiveness Data and Information Set (HEDIS) measures developed by the National Committee for Quality Assurance (NCQA), we examined quality of care for cancer screening, diabetes, and asthma among all eligible non-dual North Carolina Medicaid recipients by race and ethnicity.*

Results: *In comparison to non-Latino whites, non-Latino African Americans had higher rates of screening for breast cancer (40.1% vs. 36.1%), cervical cancer (60.5% vs. 54.6%), and colorectal cancer (25.5% vs. 20.6%) and lower rates of LDL testing among people with diabetes (61.8% vs. 65.1%) and appropriate asthma medication use (88.7% vs. 91.0%). A1C testing and retinal eye exam rates among people with diabetes were similar. Smaller racial/ethnic minority groups had favorable quality indicators across most measures.*

Limitations: *Comparability of findings to national population-based quality measures and other health plan HEDIS measures is limited by lack of case-mix adjustment.*

Conclusions: *For the health services examined, we did not find evidence of large racial and ethnic disparities in quality of care within the North Carolina Medicaid program. There is substantial room for improvement, however, in cancer screening and preventive care for Medicaid recipients as a whole.*

Keywords: *disparities; quality of care; Medicaid; cancer screening; chronic disease*

Medicaid is the largest provider of health insurance for low-income and minority populations in the United States and has both a responsibility and a vested interest to address health care disparities.[1] According to the 2006 National Healthcare Disparities Report, which tracks the extent to which minority populations receive evidence-based care for specific health care services, African Americans receive poorer quality of care than whites for the majority of core measures. Despite increasing national attention to health care disparities, quality differences continue to worsen for lower income people across two-thirds of core measures and for racial and ethnic minorities across one-third of measures.[2] Disparities are also well-documented across payer type; nationally, Medicaid recipients enrolled in managed care receive lower quality care than the commercially-insured population.[3]

In North Carolina, 15% of the population receives health care coverage under Medicaid. The North Carolina Division of Medical Assistance (NC DMA) is committed to monitoring the quality of health care delivered to North Carolina

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Medicaid recipients, detecting disparities where they exist, and identifying opportunities to improve health and health care for this vulnerable population. Since 2001, the NC DMA has been monitoring and reporting the Healthcare Effectiveness Data and Information Set (HEDIS) measures endorsed by the National Committee for Quality Assurance (NCQA)[4] a quality monitoring tool employed by over 90% of America's health plans to generate comparable measures of performance on important dimensions of care.[5]

Presented here are HEDIS measures for measurement year 2006 pertaining to quality and effectiveness of care. Specifically, we report the proportion of eligible non-dual Medicaid recipients who have received breast, cervical, and colorectal cancer screening, as well as recommended diabetes and asthma care. This report is unique from nationally available NCQA data in its inclusion of the entire state non-dual Medicaid population (including both fee-for-service patients and those enrolled in managed care) and its stratification of results by race and ethnicity.

Methods

Seven quality of care measures derivable from administrative data alone were considered for this report: three for cancer screening, three for diabetes care, and one for asthma care. Diagnosis and procedure codes in Medicaid administrative claims data were used to identify eligible patients and recommended services, in accordance with HEDIS 2007 Technical Specifications (see Table 1).[6] Inclusion required continuous Medicaid enrollment during the measurement year (2006) for all measures. Colorectal cancer, breast cancer, and asthma care measures required continuous enrollment in the prior year (2005) as well. One gap of up to 45 days in continuous enrollment during each year was allowed. The NC DMA data warehouse contained 72 months of historical data. Exclusion criteria for some measures (such as prior hysterectomy for cervical cancer screening) might not have been identified if the occurrence was prior to this period. Persons who are eligible for both Medicaid and Medicare coverage were not considered in these analyses due to incomplete availability of Medicare claims data.

Race and ethnicity is self-reported by Medicaid recipients during enrollment. Six categories of self-reported race and nine categories of self-reported ethnicity were grouped into seven distinct race/ethnicity categories for this report for ease of comparison and to allow for sufficient size in each group. Recipients identified as Hispanic or Latino in administrative data were categorized as "Latino." Non-Latino recipients were categorized as African American, white, American Indian/Alaskan Native, Asian/Pacific Islander, other, or unreported race/ethnicity. National HEDIS means, reflecting HEDIS performance among participating managed care organizations, are reported as a point of reference,[7] though unexamined case-mix differences between North Carolina Medicaid recipients and persons enrolled in managed care plans nationally preclude direct comparison.

Results

Race and ethnicity data were unavailable for 3-7% of the eligible population across measures. African Americans and whites together comprised between 84% and 95% of the eligible population within each measure.

Results are shown in Tables 2-4. In comparison to whites, African Americans had higher rates of screening for breast cancer (40.1% vs. 36.1%), cervical cancer (60.5% vs. 54.6%), and colorectal cancer (25.5% vs. 20.6%). Among people with diabetes, rates of A1C testing and retinal eye exams were similar for African Americans and whites, but LDL cholesterol screening rates were lower among African Americans (61.8% vs. 65.1%). African Americans had slightly lower rates of appropriate asthma medication use (88.7% vs. 91.0%). Among Latino, American Indian/Alaskan Native, and Asian/Pacific Islander Medicaid recipients, observed rates of cancer screening and diabetes and asthma care were similar or better than rates observed among whites.

Appropriate asthma medication use among North Carolina Medicaid recipients exceeded that of national Medicaid managed care and commercially insured populations. For all other quality of care indicators, North Carolina Medicaid rates were substantially lower than these national comparison groups.

Discussion

Stratification of HEDIS quality of care measures by race and ethnicity did not reveal a consistent pattern of disparities within the North Carolina Medicaid population. African Americans had better rates of cancer screening than whites, similar quality of diabetes care, and slightly worse asthma care. These findings differ from national estimates which suggest lower rates of colorectal cancer screening and diabetic A1C testing, similar rates of mammography, and higher rates of cervical cancer screening and diabetic eye exams among African Americans compared to whites in the general population.[2] Medicaid recipients constitute a lower-income segment of the general population, with a higher prevalence of chronic disease and disability which may present additional barriers to receiving recommended screening tests. Importantly, however, Medicaid recipients have health care coverage for all services examined in these measures. Therefore the interplay between socioeconomic status, health status, access to care, and race/ethnicity may be expected to operate differently within a Medicaid population than the general US population.

Among American Indians/Alaskan Natives, Latinos, and Asians/Pacific Islanders, quality of care also appears to exceed that of whites across most measures. Exceptions are lower rates of cervical cancer screening among Asians/Pacific Islanders and A1C testing among American Indians/Alaskan Natives. Firm conclusions cannot be drawn about these smaller race/ethnicity groups, however, because of the much larger number of recipients with unreported race and ethnicity. It is unclear why recommended diabetes care and cancer screening rates were highest among recipients with unreported race and ethnicity, with the exception of cervical cancer. Any association between race/ethnicity and the likelihood of that information being recorded in Medicaid administrative data could create significant error in reported rates for the smaller race/ethnicity groups.

The inherent limitations of using paid claims data to assess quality of care must also be acknowledged. Diagnostic coding for asthma or diabetes on claims submitted to Medicaid were required to identify individuals eligible for these measures. Coding for bilateral mastectomy, hysterectomy, or colon cancer in Medicaid claims history was required to appropriately exclude

Table 1.
HEDIS Measures and Descriptions

HEDIS Measure	Description
Cancer Screening	
Breast	The percentage of women 40-69 years of age who had one or more mammograms during the measurement year or the year prior to the measurement year. Women who had a bilateral mastectomy were excluded.
Cervical	The percentage of women 21-64 years of age who received one or more Pap tests during the measurement year or the two years prior to the measurement year. Women who had a hysterectomy were excluded.
Colorectal	The percentage of adults 50-80 years of age who had appropriate screening for colorectal cancer, defined as any one of the following: fecal occult blood test during the measurement year; flexible sigmoidoscopy during the measurement year or the four years prior to the measurement year; double contrast barium enema during the measurement year or the four years prior to the measurement year; or colonoscopy during the measurement year or the nine years prior to the measurement year. (Only 72 months of historical data were available for identifying colonoscopies.) Recipients with a diagnosis of colorectal cancer or a total colectomy were excluded.
Comprehensive Diabetes Care	
A1C Testing	The percentage of members 18-75 years of age with diabetes (type 1 and type 2) who had an A1C test performed during the measurement year.
LDL-C Testing	The percentage of members 18-75 years of age with diabetes (type 1 and type 2) who had an LDL-C screening test performed during the measurement year.
Retinal Eye Exams	The percentage of members 18-75 years of age with diabetes (type 1 and type 2) who had a retinal or dilated eye exam by an eye care professional (optometrist or ophthalmologist) in the measurement year. (HEDIS specifications also allow a negative retinal exam in the year prior to the measurement year as evidence of screening. Exam results are not available in the NC DMA data, so this criterion was not used.)
Asthma Care	
Use of Appropriate Medications for People with Asthma	The percentage of members 5-56 years of age who were identified as having persistent asthma and who were appropriately prescribed medication during the measurement year. Persistent asthma is identified when a recipient has met at least one of the following four criteria during both the measurement year and the year prior to the measurement year: had at least one emergency room visit with asthma as the principal diagnosis; had at least one acute inpatient discharge with asthma as the principal diagnosis; had at least four outpatient asthma visits with asthma as one of the listed diagnoses and at least two asthma medication dispensing events; and had at least four asthma medication dispensing events (i.e., an asthma medication dispensed on four occasions). "Appropriately prescribed medications" include at least one dispensed prescription for inhaled corticosteroids, nedocromil, cromolyn sodium, leukotriene modifiers, or methylxanthines during the measurement year. Recipients who had been diagnosed with emphysema or chronic obstructive lung disease were excluded.

individuals from cancer screening measures. Any screening services performed but not reimbursed by Medicaid could not be counted. It is unlikely, however, that such omissions are common enough to have created significant error in the observed rates. Findings represent only continuously-enrolled non-dual Medicaid recipients and may not be generalizable to

Table 2.
Proportion of Non-Dual North Carolina Medicaid Recipients Who Have Received Recommended Cancer Screenings, by Race/Ethnicity and 2006 National HEDIS Mean

	Breast Cancer		Cervical Cancer		Colorectal Cancer	
	Number of Eligible Individuals	Percent Screened	Number of Eligible Individuals	Percent Screened	Number of Eligible Individuals	Percent Screened
African American	19,043	40.1	57,799	60.5	18,825	25.5
White	19,035	36.1	53,378	54.6	24,858	20.6
American Indian/Alaskan Native	764	44.6	2,302	61.4	776	32.6
Latino	452	47.3	1,807	59.6	420	29.5
Asian/Pacific Islander	316	38.6	891	53.2	350	22.0
Other	836	26.9	1,707	46.0	1,144	18.3
Unreported Race/Ethnicity	2,653	44.9	3,588	45.6	2,767	36.1
Total Eligible North Carolina Medicaid Recipients	**43,099**	**38.5**	**121,472**	**57.2**	**49,140**	**23.6**
2006 National Medicaid MCO HEDIS mean		53.9		65.0		n/a
2006 National Commercial Plan HEDIS mean		72.0		81.8		52.3

Table 3.
Proportion of Non-Dual North Carolina Medicaid Recipients with Diabetes Who Have Received Recommended Services, by Race/Ethnicity and 2006 National HEDIS Mean

	A1C Testing		LDL-C Screening		Retinal Eye Exam	
	Number of Eligible Individuals	Percent Receiving Service	Number of Eligible Individuals	Percent Receiving Service	Number of Eligible Individuals	Percent Receiving Service
African American	12,369	72.6	12,369	61.8	12,369	39.8
White	11,026	72.4	11,026	65.1	11,026	38.8
American Indian/Alaskan Native	448	69.6	448	66.7	448	38.8
Latino	434	77.4	434	67.3	434	43.3
Asian/Pacific Islander	189	79.9	189	66.1	189	45.0
Other	399	66.9	399	59.6	399	39.3
Unreported Race/Ethnicity	1,361	79.8	1,361	70.8	1,361	44.5
Total Eligible North Carolina Medicaid Recipients	**26,226**	**72.9**	**26,226**	**63.8**	**26,226**	**39.7**
2006 National Medicaid MCO HEDIS mean		76.2		80.5		48.6
2006 National Commercial Plan HEDIS mean		87.6		92.3		54.8

persons with intermittent Medicaid coverage or to those over age 65 or on Social Security Disability with Medicare coverage.

Mean values for National HEDIS indicators for Medicaid managed care and commercial plans were provided in this report as a point of reference, but direct comparisons should be made with caution. To our knowledge, North Carolina is unique in publicly reporting HEDIS measures for both managed care and fee-for-service Medicaid recipients. Thus North Carolina measures include patients with more extensive chronic disability who may be excluded from managed care participation in other states. HEDIS methodology does not adjust for risk or case-mix differences in the population. Case mix differences may also confound differences observed across race/ethnicity groupings in these analyses.

Many factors may contribute to favorable rates of screening among minority populations in North Carolina. The Community Care of North Carolina (CCNC)[8] system has strived to increase awareness of evidence-based practices throughout the state over the past decade, particularly in relation to diabetes and asthma care for Medicaid recipients. It is conceivable that CCNC participation and the impact of quality improvement efforts may have been greatest in the areas that serve more diverse populations. It is also plausible that local outreach efforts to raise awareness about prevention, supported through the North Carolina Office of Minority Health and Health Disparities, Division of Public Health, the faith-based community, and others, may have been more concentrated or more effective in predominantly minority communities. In fact, there may be a need for more aggressive prevention efforts targeting low-income whites. Observed differences in screening rates could reflect differential attention to preventive services on the part of health care providers, or a greater propensity to adhere to screening recommendations among minorities with Medicaid coverage. These potential factors could not be explored with available data and warrant further study.

These findings provide reassurance that, for the particular health services examined, large racial/ethnic disparities in quality of care are not readily apparent within the North Carolina Medicaid program. However, substantial deficiencies in care for Medicaid recipients as a whole are evident. A large majority of eligible patients have not been screened for breast and colorectal cancer, and over 40% have not been screened for cervical cancer. More than 25% of Medicaid enrollees with diabetes are not receiving recommended tests to monitor blood sugar control and cholesterol levels, and over 60% are not receiving routinely recommended eye care. Addressing racial/ethnic and income-related health disparities in North Carolina will require improved quality of care for all Medicaid recipients. Expansion of existing quality improvement efforts, to more broadly address preventive care and to engage additional providers and patients in better management of chronic disease, may move us further toward the goal of eliminating health care disparities in North Carolina. **NCMJ**

Table 4.
Proportion of Non-Dual North Carolina Medicaid Recipients with Persistent Asthma Who Have Received Appropriate Medications, by Race/Ethnicity and 2006 National HEDIS Mean

	Number of Eligible Individuals	Percent with Appropriate Medications
African American	6,977	88.7
White	5,882	91.0
American Indian/Alaskan Native	387	92.5
Latino	437	91.8
Asian/Pacific Islander	39	92.3
Other	551	93.1
Unreported Race/Ethnicity	1,053	91.2
Total Eligible North Carolina Medicaid Recipients	**15,326**	**90.1**
2006 National Medicaid MCO HEDIS mean		85.7
2006 National Commercial Plan HEDIS mean		89.9

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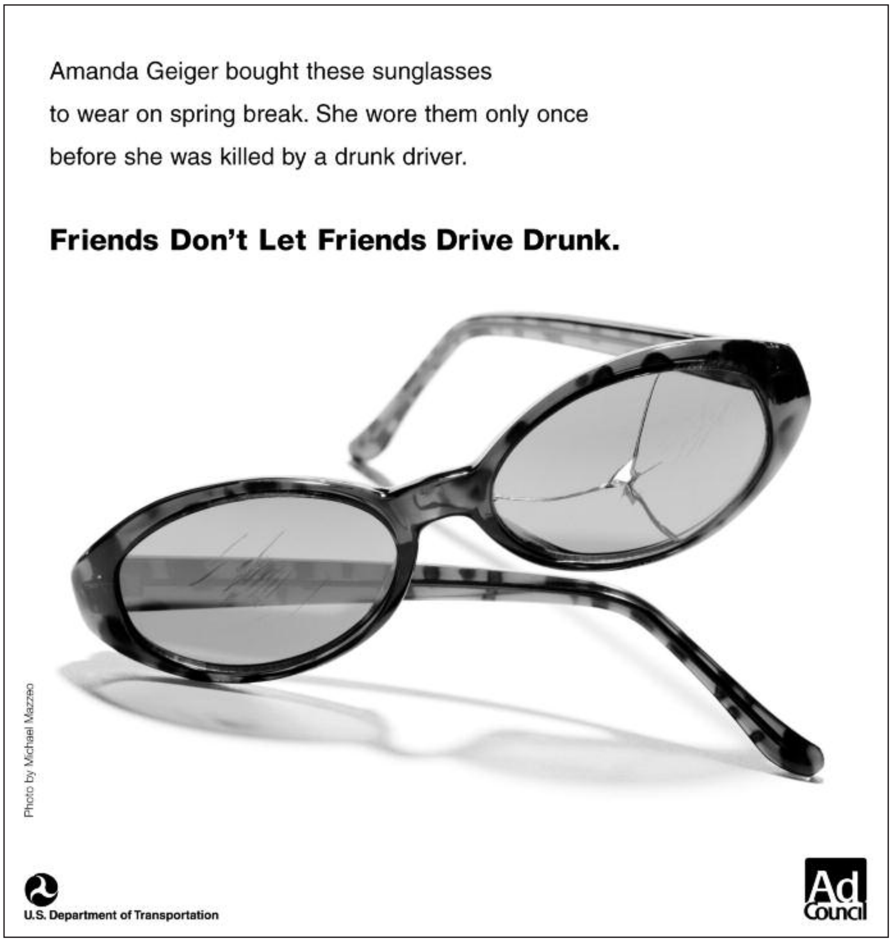

PEER-REVIEWED ARTICLE

Community-Acquired MRSA Infections in North Carolina Children:

Prevalence, Antibiotic Sensitivities, and Risk Factors

Adam Shapiro, MD; Sudha Raman, PT, MSc; Marilee Johnson, MBA, MT; Mark Piehl, MD, MPH

Abstract

Background: *The incidence of community-acquired methicillin-resistant* Staphylococcus aureus *(CA-MRSA) infections in children has increased dramatically over the past decade. CA-MRSA infections are often resistant to standard outpatient antibiotics and present a large burden to the health care system and to afflicted families.*

Objectives: *Our aims were to characterize the patterns of CA-MRSA resistance to common antibiotics and to identify significant risk factors for CA-MRSA infection in healthy children at a large urban hospital. Additional goals were to discover the prevalence of CA-MRSA in the institution and to observe any notable trends surrounding CA-MRSA infection in the facility.*

Methods: *We retrospectively analyzed the medical records of patients under 18 years of age in the WakeMed Health and Hospitals system with cultures positive for* Staphylococcus aureus *over a period of seven and a half months in 2006. Cases were classified as community-acquired, and we then analyzed risk factors and examined trends surrounding CA-MRSA infection.*

Results: *A total of 229 cases of* Staphylococcus aureus *infection were identified over the study period, of which 142 were CA-MRSA, a prevalence of 75.9% (95% CI, 69.5-82.3). Our CA-MRSA isolates were 98.6% sensitive to trimethoprim-sulfamethoxasole, 94.4% sensitive to tetracycline, 90.8% sensitive to clindamycin, and 59.9% sensitive to levofloxacin. Risk factors for CA-MRSA infection included parental employment in a school or daycare, family history of boils or MRSA, and antibiotic use by children in the past six months.*

Limitations: *Our definition of CA-MRSA is based on retrospective data from patient and family verbal histories in the medical record. We did not perform molecular genotyping of MRSA samples to confirm community-associated strains.*

Discussion: *CA-MRSA is now the predominant strain of* Staphylococcus aureus *causing childhood infections in this central North Carolina hospital. Thus, standard antibiotic therapy with penicillins or first generation cephalosporins is no longer adequate for most pediatric skin and soft tissue infections in this population. Trimethoprim-sulfamethoxasole and clindamycin both appear as reasonable alternatives for empiric therapy.*

Keywords: *MRSA; methicillin-resistant; community-acquired; North Carolina*

Methicillin-resistant *Staphylococcus aureus* (MRSA) has become a commonly encountered pathogen in medical practices around the world. Initially considered an organism acquired strictly in health care settings, community-acquired MRSA (CA-MRSA) strains now afflict patients without previous hospital exposures. Most CA-MRSA outbreaks reported before 1990 occurred in specific populations such as Native Americans, intravenous drug users, and prison inmates, but over the past decade, the prevalence of this organism has risen dramatically in the general population.[1-3] Thousands of cases of CA-MRSA infection have been documented, and the organism has been increasingly blamed for superficial and invasive infections in pediatric patients.[4-8] Furthermore, the majority of afflicted children do not have readily identifiable risk factors for MRSA colonization or infection.[9] While some studies have demonstrated socioeconomic risk factors for MRSA colonization or infection, there remains no definite consensus as to why otherwise healthy children acquire these resistant bacteria.[10-12]

At one pediatric hospital center in Texas, CA-MRSA is now responsible for 76% of all skin and soft tissue infections.[13] Similar reports of soaring CA-MRSA infection rates in pediatrics have

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been published across the country, and many pediatricians have altered their prescribing practices to address this increasing problem in the outpatient arena. While generally resistant to beta-lactams and cephalosporins, CA-MRSA is usually susceptible to alternative oral medications such as trimethoprim-sulfamethoxasole, clindamycin, and tetracycline. However, even with adequate outpatient antibiotic therapies, many children still require hospitalization, intravenous antibiotics, and surgical drainage of their lesions.

Despite the increasing burden of CA-MRSA on pediatric patients and on the health care system, the exact prevalence of this organism is still not known in many areas of the country. In North Carolina, one study has examined the CA-MRSA prevalence in children, but this was done in an emergent setting and only investigated cutaneous infections.[14] Furthermore, this study did not release the full antibiotic sensitivity panels on their CA-MRSA isolates. For this study, our primary goals were to characterize the pattern of CA-MRSA resistance to commonly used antibiotics and to discover clinically significant risk factors for infection in our pediatric patients. Secondary goals were to calculate the prevalence of this organism in our pediatric center and to observe any notable trends surrounding CA-MRSA infection in otherwise healthy children.

Methods

All patient data for this study was obtained through the WakeMed Health and Hospitals system in Raleigh, North Carolina and the WakeMed Institutional Review Board approved this study. WakeMed is a tertiary care center with 24 pediatric inpatient beds, a pediatric intensive care unit, a level III neonatal intensive care unit, a busy outpatient pediatric clinic, and a dedicated pediatric emergency department with over 40,000 emergency room visits annually. WakeMed receives pediatric referral patients from numerous outside clinics and hospitals throughout central North Carolina and provides advanced subspecialty care in many areas of pediatrics. It is also affiliated with the School of Medicine at the University of North Carolina at Chapel Hill.

We retrospectively analyzed the medical records of patients under 18 years of age with a microbiology culture positive for *Staphylococcus aureus* from January 1, 2006 to August 15, 2006. Patient records were reviewed by a single clinician over a two-month period. Over 98% of the patients resided within a 30 mile radius of the WakeMed Raleigh campus, an area that includes portions of Wake, Johnston, Durham, Harnett, Franklin, Nash, and Granville counties.[15] This grouping of counties included urban, suburban, and rural communities. Positive MRSA samples were obtained from both inpatient and outpatient subjects in a variety of locations including hospital wards, intensive care units, emergency rooms, operating rooms, and pediatric clinics. Susceptibilities were reported using Clinical and Laboratory Standards Institute (formerly NCCLS) breakpoint guidelines.[16] Microbial susceptibilities to ampicillin-sulbactam, cefazolin, clindamycin, erythromycin, levofloxacin, oxacillin, penicillin G, tetracycline, trimethoprim-sulfamethoxasole, and vancomycin were tested on each isolate. Inducible resistance to clindamycin through a positive D-test was also reported. Linezolid results were not routinely reported by our microbiology laboratory, and oxacillin resistance was considered synonymous with methicillin resistance. Study data were tracked in a Microsoft Access database and then classified as community-acquired based on patient histories, which were available in the medical record. No direct patient or family interviews were conducted. Statistical analysis was performed using SAS software. We compared the prevalence and antibiotic resistance of CA-MRSA isolates against those of community-acquired methicillin-susceptible *Staphylococcus aureus* (CA-MSSA) samples. The main outcome of interest was the prevalence of CA-MRSA. Prevalence ratios and 95% confidence intervals for a priori demographic, patient history, and infection characteristic risk factors were estimated using unadjusted log-prevalence regression. Statistical significance was evaluated at the $\alpha = 0.05$ level.

For the purposes of this study, infections were considered to be community-acquired if: (1) subjects had no hospital admissions one year prior to their *Staphylococcal aureus* culture; (2) subjects had no chronic diseases or major diagnoses other than asthma, mild eczema, or attention-deficit hyperactivity disorder; and (3) the positive culture was from a lesion that was clinically apparent at the time of admission and was the primary reason for admission. We classified cultures obtained from outpatient surgical procedures as community-acquired if they also met these above criteria. Infections were excluded from community-acquired data analysis if any one of the three above criteria were not met, if the sample was from a child in the neonatal intensive care unit, if the subject lived in a long-term care facility, or if the child had a past history of MRSA infection.

Results

A total of 273 *Staphylococcus aureus* cultures were obtained during the study period, of which 98 were methicillin-susceptible and 175 were methicillin-resistant. During the chart review, 12 cases had *Staphylococcus* urine samples with bacterial colony counts lower than 10,000 and were excluded. Eighteen cases had no clinical information related to the *Staphylococcal* culture in the chart and were also excluded. Six patient charts could not be located for review, and another eight charts had incorrect medical record numbers and were not included. Thus, the final number of records reviewed was 229. Of these 229 files, 42 did not meet the study criteria for community-acquired organisms and were not included in the statistical analysis. Ultimately 45 CA-MSSA cases and 142 CA-MRSA cases were integrated into the final statistical analysis.

In the analyzed data, 76% (142 of the 187 total cases) of the community-acquired *Staphylococcus aureus* infections were MRSA (95% CI, 69.5-82.3). Resistance patterns of CA-MRSA were as follows: 1.4% resistant to trimethoprim-sulfamethoxasole, 5.6% resistant to tetracycline, 9.2% resistant to clindamycin, and 35.2% intermediately resistant to levofloxacin with 4.9% highly resistant to levofloxacin (see Table 1). There were six cases of inducible clindamycin resistance in our study (D-test positive with erythromycin), but these were categorized as clindamycin-resistant for the purpose of data analysis.

Table 1.
Proportion of CA-MRSA and CA-MSSA Isolates Resistant to Other Antibiotics

Antibiotic	CA-MRSA N = 142 n (%)	CA-MSSA N = 45 n (%)
Trimethoprim-Sulfamethoxasole	2 (1.4)	0
Tetracycline	8 (5.6)	1 (2.2)
Clindamycin	13 (9.2)	4 (8.9)
Levofloxacin – Total	57 (40.1)	2 (4.4)
Levofloxacin - Intermediate	50 (35.2)	2 (4.4)
Levofloxacin - High	7 (4.9)	0

Table note: Percentages may not add to 100% due to missing values.

We grouped infection location by body region (head, trunk/extremity, groin/buttock, and non-skin or soft tissue) for analysis. A groin/buttock infection was more likely to contain CA-MRSA than a trunk/extremity infection; however, this predilection was not statistically significant. We also examined the incidence of non-skin or soft tissue infections (NSST), which were defined as positive cultures in blood, cerebrospinal fluid, urine, bone, joint, pharynx, sputum, or lymph nodes. We found nine cases of NSST infection with CA-MRSA and six cases of NSST with CA-MSSA. There were no significant patterns or trends noted in our NSST infections in this small sample.

Within the demographic analysis, CA-MRSA was less prevalent among Latino patients (56.3%) as compared to white patients (76.8%), with an odds ratio (OR) of 0.73 (95% CI, 0.47-1.15). African Americans showed a slightly higher prevalence of CA-MRSA infection (83.5%) as compared to white patients. The OR was 1.09 (95%CI, 0.93-1.27). Patients with parents who worked in schools or daycares were at significantly increased risk of CA-MRSA illness (100%) compared to those with parents working in an office (64.5%), with an OR of 1.55 (95% CI, 1.19-2.01). Children with parents working in health care or medical fields were not at significantly increased risk for MRSA infections (84.6%) as compared to those whose parents worked in offices. The OR was 1.31 (95% CI, 0.96-1.79). Children with unemployed parents were not found at statistically increased risk of CA-MRSA infection (83.6%) as compared to employed parents (79.2%), with an OR of 1.06 (95% CI, 0.91-1.22). MRSA was more prevalent among Medicaid patients (80.2%); however, this was not significantly more than those with private insurance (73.3%), with an OR of 1.09 (95% CI, 0.92-1.30). All of these data, as well as data for CA-MSSA risk factors, are presented in Table 2.

Additional risk assessment revealed that children who received antibiotics in the six months prior to their positive culture were more likely to be infected with CA-MRSA (31% overall had recent antibiotics; CA-MRSA among those with recent antibiotics was 86.2%, CA-MRSA among those without was 71.3%, with an OR of 1.21 (95% CI, 1.04-1.41). Patients whose family members had a history of MRSA infection or a history of skin boils were also at significantly greater risk of CA-MRSA infection (88.9%) compared to those without (73.8%). The OR was 1.21 (95% CI, 1.02-1.42). Children with personal histories of cellulitis were not at significantly increased risk of CA-MRSA infection. CA-MRSA among those with a positive history was 85.2%, while prevalence among those without was 74.4%, with an OR of 1.15 (95% CI, 0.96-1.37) (see Table 2).

Discussion

Over the past decade, CA-MRSA infection has become a quickly growing problem in pediatric hospitals across the nation. Pediatric institutions from California, Alabama, Rhode Island, Tennessee, Illinois, and Texas have all published articles reporting CA-MRSA infection rates between 20-76% of their overall *Staphylococcal* infection numbers.[4,5,8,17,18] While our methods and findings are not identical to these previously published reports, our study confirms that CA-MRSA has indeed established itself as the primary cause of skin and soft tissue infections in the children of this North Carolina facility. The CA-MRSA infection rate of 75.9% (95% CI, 69.5-82.3) is one of the highest percentages reported in the pediatric literature over the past several years. The pediatric centers who reported CA-MRSA rates before 2006 have not published subsequent studies with updated prevalence rates. Thus, our high infection prevalence may demonstrate more CA-MRSA in North Carolina than other states, or it may reflect recent increases in CA-MRSA infections across many states. Further investigation is warranted to determine the current prevalence at hospital and community levels from state to state.

These findings suggest that antibiotic treatment with beta-lactam and cephalosporin drugs is no longer appropriate for children with suspected gram-positive infections in this institution, and this may also be true for hospitals with similar populations throughout North Carolina. Alternative antibiotics such as trimethoprim-sulfamethoxasole, clindamycin, or tetracycline are more appropriate empiric choices for skin and soft tissue infections. More serious infections requiring

Table 2.
Risk Factors for CA-MRSA and CA-MSSA Infection

	CA-MRSA N = 142 n (%)	CA-MSSA N = 45 n(%)	PR[a]	95% CI	p-value
Gender[b]					
Male (reference)	63 (76.8)	19 (23.2)			
Female	78 (78.0)	22 (22.0)	1.0	0.87-1.19	0.85
Age[c]					
0 to 1 years (reference)	20 (69.0)	9 (31.0)			
>1 to 5 years	44 (71.0)	18 (29.0)	1.03	0.77-1.38	0.85
>5 to 13 years	34 (79.1)	9 (20.9)	1.15	0.86-1.53	0.35
>13 to 18 years	39 (83.0)	8 (17.0)	1.2	0.91-1.59	0.19
Ethnicity[c]					
White (reference)	53 (76.8)	16 (23.2)			
African American	76 (83.5)	15 (16.5)	1.09	0.93-1.27	0.3
Latino	9 (56.3)	7 (43.8)	0.73	0.47-1.15	0.18
Other	3 (60.0)	2 (40.0)	0.78	0.38-1.62	0.51
Insurance Status[c]					
Medicaid (reference)	97 (80.2)	24 (19.8)			
Non-Medicaid	44 (73.3)	16 (26.7)	1.09	0.92-1.3	0.32
Parent Occupation Status[d]					
Employed (reference)	84 (79.2)	22 (20.8)			
Unemployed	51 (83.6)	10 (16.4)	1.06	0.91-1.22	0.48
Parent Occupation[d]					
Office (reference)	20 (64.5)	11 (35.5)			
School/daycare	**17 (100.0)**	**0**	**1.55**	**1.19-2.01**	**0.005**
Medical	22 (84.6)	4 (15.4)	1.31	0.96-1.79	0.09
Unemployed	51 (83.6)	10 (16.4)	1.3	0.98-1.72	0.04
Other[e]	25 (78.1)	7 (21.9)	1.21	0.88-1.67	0.23
Antibiotic Use					
No recent use (reference)	92 (71.3)	37 (28.7)			
Recent use	**50 (86.2)**	**8 (13.8)**	**1.21**	**1.04-1.41**	**0.01**
Family History of MRSA or Boils					
No (reference)	118 (73.8)	42 (26.3)			
Yes	**24 (88.9)**	**3 (11.1)**	**1.21**	**1.02-1.42**	**0.02**
Personal History of Cellulitis					
No (reference)	119 (74.4)	41 (25.6)			
Yes	23 (85.2)	4 (14.8)	1.15	0.96-1.37	0.14
Location of Infection[b]					
Trunk/extremities (reference)	70 (74.5)	24 (25.5)			
Head	16 (66.7)	8 (33.3)	0.9	0.66-1.22	0.48
Groin/buttock	42 (85.7)	7 (14.3)	1.15	0.98-1.36	0.09
Non-skin or soft tissue (NSST)	9 (60.0)	6 (40.0)	0.81	0.52-1.24	0.3

Table note: Numbers that are presented in bold are statistically significant.

a PR = prevalence ratio (95% confidence interval).

b Data missing on 5 patients.

c Data missing on 6 patients.

d Data missing on 20 patients.

e Other occupation includes manufacturing (4), retired (2), self-employed (2), retail (13), and restaurant (11).

hospital admission may necessitate empiric intravenous clindamycin or vancomycin until susceptibilities are determined. Levofloxacin may be another possible outpatient therapy as the number of highly-resistant CA-MRSA cases was small. Yet there was a large percentage of intermediate resistance to levofloxacin, and it remains unclear if customary treatment dosages would overcome this resistance in vivo. We also included six cases of inducible clindamycin resistance (D-test positive) in our analysis, in which we found nearly 10% of all CA-MRSA cases resistant to clindamycin. Since we cannot determine the true in vivo resistance of these D-test positive cases, the actual rate of clindamycin resistance in our community may be closer to 7%. Finally, treatment with linezolid would also likely be adequate therapy for CA-MRSA infection, but our laboratory did not routinely report results with this drug.

Minority ethnicity and lower socioeconomic status have both been demonstrated in previous studies to be risk factors for CA-MRSA infection.[10-12] While our data did show a trend toward increased risk among African American patients as compared to white patients, we did not find employment status or other demographic factors to be significant risk factors for CA-MRSA. We did find that CA-MRSA infections were less common among Latino children when compared to non-Latino white children; however, this did not reach statistical significance and is based on a very small number of Latinos in the study population. To our knowledge this trend has not been previously reported, and possible environmental or sociological factors responsible for this decreased infection risk were not readily apparent in our data or in the published literature.

There has been past suspicion that parental occupation may play a role in a child's risk for CA-MRSA infection, yet no studies have conclusively proven this theory. We did find that children with parents working in schools or daycares were at significantly increased risk of CA-MRSA illness as compared to those who worked in an office. This likely stems from subclinical colonization of the parent at work, with transmission to the child at home. Conversely, it is possible that children with parents working in schools or daycares are themselves more likely to be enrolled in school or daycare, and direct exposure in those settings could also explain their increased risk. Past studies examining the rates of CA-MRSA colonization in children attending daycare centers have shown significant disease burdens that often mirror increasing MRSA rates in the general community.[19,20] One might surmise that a child of a parent working in the health care field would also be at higher risk for CA-MRSA infection, yet an elevated prevalence in this group as compared to those who work in an office was not a significant finding in this study. Data on parental occupation was not obtained for 21 subjects. Therefore, power was lost to detect these expected differences assuming that the missing data was absent at random.

In our study, CA-MRSA was more common in soft tissue infections of the groin/buttock region, but this trend did not reach statistical significance. One possible explanation for this increased groin/buttock prevalence is that primary care physicians may be more likely to refer most groin lesions to a pediatric surgeon for incision and drainage in the hospital setting. There may be other unrecognized reasons influencing groin/buttock area CA-MRSA infections, but at present there are no published reports addressing these risk factors.

Finally, several well-regarded risk factors for CA-MRSA infection were examined in our analysis. MRSA was more prevalent among children with personal histories of cellulitis, children with household exposure to others with past MRSA infection or skin boils, and children with a history of recent antibiotic use. The prevalence of MRSA was increased significantly for the latter two factors. Our finding that patients who received antibiotics in the previous six months were more likely to be infected with CA-MRSA than those who had not suggests that the overuse of outpatient antibiotics may be playing a large role in the acquisition of this resistant organism. In the majority of subjects, the reason for this recent antibiotic use was unknown. Data on household exposures and past history of cellulitis was gathered only if there was mention of these risk factors in the chart review. Many charts were missing this information and therefore were classified as negative. Thus, there could be a larger proportion of subjects with these significant risk factors who were not evident through our retrospective data collection. Although we were able to see a significant positive association of family history of boils or MRSA with MRSA infection, it is likely that if the misclassification was nondifferential, the results of these factors may be an underestimate of the true value.

Limitations

The major limitation of this study is our definition of CA-MRSA cases based solely on retrospective data from patient and family verbal histories in the medical record. Several other hospitals operate in the immediate area, and verbal history alone may have omitted recent patient admissions to these facilities, which would have changed the subject's classification to non-community-acquired for our study. We did not conduct genotyping of MRSA cultures, which would have provided better categorization of samples as community-acquired in origin. Without genotyping, infections in children with past MRSA were considered hospital-associated and removed from our data analysis. Despite the loss of sample size, we feel that being stringent in our definition of the study population was warranted to insure the integrity of our conclusions. Overall, we believe that our definition of community-acquired infection includes all the necessary criteria to adequately analyze our data. Moreover, we feel our criteria are similar to those used in recent published studies addressing CA-MRSA prevalence.[4,5,8,10,16]

Another possible limitation is that the majority of patients were referred to the emergency department by their primary physicians. Thus, referral bias may have led us to overestimate the prevalence of CA-MRSA in the larger population. It is also possible that our data includes some misclassification error as the medical record review was performed by only one individual. Finally, missing parental occupation and insurance coverage data may have affected some of our conclusions on CA-MRSA risk factors by decreasing the sample size and the precision of our estimates.

Our study demonstrates that the incidence of CA-MRSA among children in this North Carolina facility is extremely high and that CA-MRSA has become the predominant strain of *Staphylococcus aureus* causing clinically significant pediatric infections. Coming from urban, suburban, and rural surrounding counties, this population appears representative of children across North Carolina. However, MRSA data from other pediatric centers throughout the state is needed in order to broadly apply our findings and conclusions. This research indicates that empiric antibiotic therapy with penicillins or cephalosporins is no longer adequate for skin and soft tissue infections in this institution and that this may be very relevant to similar sites treating children in North Carolina. Trimethoprim-sulfamethoxasole, tetracycline, and clindamycin appear to be reasonable alternatives for empiric therapy in suspected CA-MRSA infections. Children with parents employed in schools or daycares or those who received recent antibiotics are at greater risk of CA-MRSA infection, as are children with household exposures to family members with histories of MRSA infections or skin boils. **NCMJ**

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HEALTH REFORM IN NORTH CAROLINA

Health Care Reform in 2009: Full-Speed Ahead

Jonathan Oberlander, PhD

Health care reform is a politically risky pursuit. Former President Bill Clinton learned that lesson the hard way. His ambitious health plan died in Congress in 1994 without coming close to passage, and its defeat contributed to Democrats losing majority control of both houses of Congress in that year's election.

It is all the more striking, then, that newly-elected President Barack Obama is making health care an immediate priority. The Obama administration may believe that the prospects for reform will only diminish with time if the president's power fades and that the ongoing economic crisis provides an extraordinary opportunity to overhaul the health care system. In any case, the Obama team is losing little time in pushing for an overhaul of the health system. Already the new administration has convened a White House Forum on Health Care and has released a budget that calls for new funds for health reform to create a path to universal coverage. In a speech to a joint session of Congress, President Obama declared that health care reform "cannot wait, must not wait, and will not wait another year."

> ***"While the administration clearly has its eyes on the prize of comprehensive reform that expands coverage and controls costs, in the short term it has embraced health care incrementalism as an instrument of economic stimulus."***

While the administration clearly has its eyes on the prize of comprehensive reform that expands coverage and controls costs, in the short term it has embraced health care incrementalism as an instrument of economic stimulus. The American Recovery and Reinvestment Act, adopted by Congress in February 2009, contains a number of significant health care provisions. The law provides states an additional $87 billion in federal funds for Medicaid. This aid is crucial. What the historian Niall Ferguson has termed the "Great Recession" is exacting a terrible toll in the economy: over four million Americans have lost their jobs since the recession began and the national unemployment rate now stands at 8.5%. Medicaid is a counter-cyclical program, designed to expand when the economy contracts. When newly unemployed Americans (and their families) lose health insurance and become eligible for Medicaid, it puts tremendous fiscal pressure on Medicaid programs just as state tax revenues are plummeting (a casualty of the weakened economy).

For North Carolina and other states, the new federal money is imperative to finance expanding Medicaid enrollment. The federal government is also providing newly unemployed workers who have lost health insurance with a temporary subsidy to help them afford COBRA coverage so that they can continue to buy into their employer's health plan.

In addition, in February 2009 Congress passed and President Obama signed legislation reauthorizing the Children's Health Insurance Program (CHIP). The legislation provided $32.8 billion in funds over the next four and a half years so that CHIP can cover an estimated four million more uninsured children. Notably, the legislation authorized states to use federal money to cover legal immigrant children and pregnant women who have been in the country for less than five years; previously they faced a five-year waiting period before they were eligible for Medicaid or CHIP.

Finally, Congress and the administration have made a down-payment on delivery system reform. The federal government is investing $19 billion to promote the adoption of health information technology and $1 billion in comparative-effectiveness research to identify preferred treatment options.

The Obama administration and Congress have, then, already accomplished much in health reform in 2009. But the administration and key Congressional leaders want to do much more. Where does health reform go from here?

The quest for comprehensive health reform remains an uphill struggle. There are deep partisan divisions in Congress over how to remake the health care system; while health system stakeholders now voice support for reform, that support will be tested once actual legislation is drafted; and there is not yet a politically viable way to pay for universal (or even near-universal) coverage or to control costs. Indeed, President Obama's proposal to limit tax deductions for wealthier Americans to help pay for health reform is sure to face opposition in Congress.

> ***"We can, after all, say something in 2009 that has not been heard for a long time: health reform has a chance."***

Still, the Obama administration has moved quickly and boldly to make health care a priority and that provides ample grounds for optimism. We can, after all, say something in 2009 that has not been heard for a long time: health reform has a chance. **NCMJ**

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POLICY FORUM

Patient Advocacy in North Carolina

> *"For our purposes, we define patient advocacy as the wide range of interventions promoting patient-centeredness, patient safety, and patient voice in the health care system."*

Introduction

POLICY FORUM:
Patient Advocacy in North Carolina

Advocating on behalf of sick, vulnerable, or dying patients is an age-old value of our society. Family, friends, and formal organizations take on this responsibility to help those who cannot help themselves or who need assistance. As the health care system becomes more complex, this role has become more apparent to the point where we see patient advocacy as an almost necessary element in our "non-system." That necessity is compounded by the need to understand not just what is needed, but also how to gain access to the right kind of care at the right time, the right place, and at the right cost.

Our public programs Medicaid and Medicare have important patient advocacy elements and fund these activities in certain instances. This type of patient advocacy for the sick and disabled is gaining recognition as a permanent component of medical care. However, we are more familiar with programs that deal with specific types of people or special needs. Organizations such as the Red Cross advocate for victims of disasters while Planned Parenthood advocates for women's reproductive health.

The ultimate goal of patient advocacy is to improve the quality, safety, and effectiveness of health care. This is primarily done through improved patient/provider communication. Traditionally the doctor has been the sole or dominant advocate for patients but we are changing the role of the patient and we are expanding the professions and developing teams that include lay-people. What does this changing paradigm mean for those who provide and receive health care?

Patient advocacy can, at times, come close to the boundaries of issue and policy advocacy as advocacy for patients whose needs are not well understood or recognized must press for attention not only for the individual but also to their class of disease or the problem they face. The overlap of these types of advocacy occasionally creates resistance from established institutions and professions who see threats to their power or their economic position. In the context of patient advocacy we have to recognize that there are emerging problems and conditions that, when better understood, deserve our attention and support and the services and resources of our professions.

The type of patient advocacy that this issue of the *North Carolina Medical Journal* focuses on is firmly planted in past traditions of advocacy for those who need the support of society. The scope of patient advocacy, as discussed here, is clearly focused on the patient and his or her family. But it also reexamines the entire medical model and attempts to shifting the focus toward the patient—her wants and her experiences. That approach is to provide health care that is patient-centered.

In the issue brief it is clear that there are many ways to practice patient advocacy. In the pages that follow we explore everything from the patient/provider interaction, to access to health care and health insurance. We learn from the experience of others that one can be an advocate for oneself or a family member, or that we can advocate by speaking out on behalf of countless others by using the law or the media. Anything that empowers the patient to make well-informed decisions and helps the patient to understand her options and to know her rights—this is what the scope of patient advocacy encompasses.

The growing attention to patient advocacy has profited, in part, from a health care system that gives currency to the term 'byzantine.' From multiple and conflicting professionals with different theories of care and cure to co-pays to deductibles to self-directed plans to diagnoses to prescriptions that turn into polypharmacy—there is simply too much for a reasonable citizen to understand. The aim of patient advocacy is to help guide the patient and her family through the maze and to ease the confusion and discomfort at every turn.

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A Dedication in Memory of Michelle Mayer

Barbara K. Rimer, DrPH, MPH

Michelle Mayer, PhD, died on October 11, 2008 at the far-too-young age of 39, but her contributions to patient advocacy live on. Dr. Mayer was a research assistant professor in health policy and management in the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill and a research fellow at the Cecil G. Sheps Center for Health Services Research.

Whether the subject was creating access to appropriate treatments, expanding research for particular diseases, removing the stigma of illness, improving patient-provider communication, opening a window into rare diseases, or exploring her own experience with illness in a way that opened the door for other patients, Michelle Mayer changed how we think about life and death. As a patient advocate, she reshaped how we think about and confront illnesses.

I came to know Michelle through the compelling blogs, newspaper, and journal articles she wrote during her illness and up until a couple days before her death. Her blog entries in *Diary of a Dying Mom*[1] were incredibly insightful if sometimes painful to read. She wrote with brutal honesty and compelling clarity about coping with a sometimes unbearable disease, scleroderma. In her introduction, she wrote: *I believe that, as a culture, we shy away from anything surrounding death and, consequently, deprive ourselves of all the lessons inherent in the dying and grieving process. This is not my version of "The Last Lecture." It is my heart, my thoughts, my joys, and my fears as they unfold along this journey. My hope is that you will find some of it useful on your own life's journey. I hope that sharing my experiences will help not only those struggling with terminal illnesses but also those who are blessedly healthy.* An estimated 115,000 people read and were touched by her website and print entries. She also wrote scholarly articles for professional audiences (for example, see "On being a 'difficult' patient").[2] A tribute to Dr. Mayer in Health Affairs highlighted her profound impact and contributions.[3]

Michelle taught us what it means to live with a catastrophic disease that attacks so much of the body. I read what would be her last blog entry a couple of days before her death, knowing that the end was near, but willing her to live on. I returned to her blog two days later, hoping to find her words instead of silence. But there would be no more words. In a message sent after Michelle's death, her husband, Dr. William Steinbach wrote about how she dealt with the disease and almost constant pain: *Never to conceal it, but to not let it overtake her spirit. She taught us many things about living, and now taught us how to die with grace and dignity.* Michelle shared the lessons she learned from living with her illness with other patients, physicians, family members, friends, and many others. She showed us that we, too, could learn from her lessons and turn them into positive actions.

Michelle grew up in northeast Philadelphia and attended Nazareth Academy High School which has established a scholarship in her honor.[4] She graduated summa cum laude from the University of Pennsylvania with a BSN in nursing. She earned an MPH in health behavior and health education and then a PhD in health policy and administration from the University of North Carolina at Chapel Hill School of Public Health. Active in a number of organizations, she founded the Elizabeth Ministry at St. Thomas More Catholic Church. The ministry supports women and their families during the childbearing years. Sister Mary Joan Jacobs, principal of Nazareth Academy High, says, Michelle's *greatest love was her family—her husband Bill, children Amelia and Aidan, her parents, her brothers, and her friends*. Our thoughts are with them all.

It is fitting that this issue is dedicated to Michelle Mayer. Throughout her adult life, and especially during her illness, Michelle was a remarkable advocate whose impact reached people all over the world. She wrote: *I suppose that in some ways I became a more calculating person. I did many things purposefully, knowing that my remaining time was short... In many ways, my illness has been my life's director, showing me how to play my part so that it was genuine and real. It taught me to listen to my heart rather than the brain that ruled my world during my healthy years.* Michelle's courageous advocacy lives on as a gift to all she left behind. As she wrote in her final post, *until we meet again, Godspeed*.

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Health Reform: An Invitation to Contribute to the Discussion

The run up to the November election brought a lot of attention to health reform. Both major candidates presented relatively complete plans for major changes in the way we pay for health care and how we structure our health care delivery system. The appointments by President Obama point to a sustained effort to implement real change. This has prompted many experts and representatives of patients, providers, and payers to propose their own plans for reform. The *North Carolina Medical Journal* will be taking a part in this discussion with a section of the *Journal* devoted to articles and analyses that focus on reform. We would like to invite submissions that help the readership of the *Journal* understand why reform may be necessary, how the system should be changed, and how national reform will affect North Carolina. We invite scholarly discussions and analyses as well as commentaries that help illustrate the benefits as well as the problems that comprehensive change will bring to the costs, quality, and outcomes of health care and to the health of the people of North Carolina. The second installment of this new series starts on page 108 of this issue of the *Journal*.

North Carolina
MEDICAL JOURNAL

ISSUE BRIEF

Patient Advocacy:
Putting the Vocabulary of Patient-Centered Care into Action

Elizabeth A. French, MA; Melissa B. Gilkey, MPH; Jo Anne L. Earp, ScD

About seven years ago, when the University of North Carolina at Chapel Hill received seed funds from an alumnus to start an initiative on patient advocacy within the Department of Health Behavior and Health Education,[a] we embarked on an effort to better define the subject area, initiate a multidisciplinary focus on this topic within the School of Public Health, and mobilize leaders to advance patient advocacy's aims, scope, and reach. Over the years, we have come to see patient advocacy as a practice aimed at improving health care quality and access, particularly with regard to patient-centeredness and patient safety, by advancing the patient's perspective. The methods of patient advocacy are varied. They encompass everything from interventions that target individual empowerment and better patient-provider communication to policy development efforts that can improve health care delivery and design. Its practitioners vary as well, from patients and family members to health care providers, hospital administrators, researchers, and policymakers. This broad definition of patient advocacy was not immediately apparent to us but rather evolved over time after reflection and research with colleagues from a wide range of backgrounds. Here we recount this process to document major ideas, tensions, and traditions that have shaped the evolution of this field and to give a context for the commentaries in this issue of the *Journal*.

Two major influences guided our work from the beginning: (1) the ideas and actions of our advocate colleagues, and (2) concepts put forth in a pair of seminal reports by the Institute of Medicine of the National Academies (IOM), *To Err is Human: Building a Safer Health System* (2000) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001). Together, these books point to patient-centered care as starting and ending points for improving the quality of care delivered within our nation's health care system.

> *"The role of a patient advocate calls on the skills of the diplomat, the inquisitiveness of the educator and problem solver, and the courage of the activist to speak up in difficult situations."*

With the IOM reports in hand and with the support of a national network of advocates made up of health professionals, lawyers, heads of nonprofits, survivors of disease, and others who self-identified as patient advocates, our team at UNC: hosted two conferences, in 2003 and 2005; edited a foundational textbook;[1] conducted preliminary research on

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[a] The Scott and June Pearson Fund for Patient Advocacy was established within the Department of Health Behavior and Health Education at the UNC Gillings School of Global Public Health by Mr. Clarence Pearson and Ms. Laurie Norris in 2000.

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patient advocacy questions;[2] and developed a graduate level seminar, now in its fourth year, that has attracted students from public health, nursing, occupational therapy, pharmacy, and social work. In doing so, we have created forums for thinkers and doers from across the nation but especially with and for advocates from North Carolina. These efforts, we believe, have helped to further codify and disseminate our collective knowledge of patient advocacy's principles, methods, and the many research questions that remain unanswered.

Our first agenda item, to develop a taxonomy of the field, proved a challenge in its own right. We quickly confronted the perception, even among ourselves, that "advocacy" is a loaded term, connoting not simply methods used to right a social wrong but a potentially biased approach fueled by enthusiasm, even self-interest, rather than evidence. Part of our agenda as scholars of patient advocacy has therefore been to bring together a body of sound information to undergird its aims while also analyzing its methods to bring attention to its ethical practice.

We quickly found that no stable definition of patient advocacy was in circulation, and that the term itself was charged with political meaning. *Patient*, we came to understand, connotes a level of passivity that many of our colleagues reject. Moreover, it may not fully capture the social and political contexts of people suffering from illness. Yet the word *client*, with its connotation of being a *customer*, much less the word *consumer*, which gestures to those who are able to shop around for their health care, seem even less adequate. For our purposes, we define *patient advocacy* as the wide range of interventions promoting patient-centeredness, patient safety, and patient voice in the health care system. Similar to those who use the term *health advocacy*, a term that embraces both patient advocacy *and* efforts to change health determinants outside the health care system, we take an ecological approach. We aim our work at all societal levels: at individual patients, their families, and providers; institutions such as hospitals and nursing homes; communities; and policies. Similar to our definition, our methods are broad, drawing on approaches familiar to those in the humanities (narratives as tools for understanding multiple perspectives), the social sciences (understanding the social context of illness), and those driven by the metrics of quality improvement.

Yet despite the richness that all these terms add to the conversation, we have retained the phrase patient advocacy because of the way the term *patient* captures a physical condition describing individuals in a weakened state or in need of a champion or mediator in the specific context of the health care system.[3] Rendered vulnerable by illness, patients given serious diagnoses often find themselves growing disoriented when plunged into a complex medical world whose rules are confusing, whose language is alien, and whose processes are too often dehumanizing. One way patients have of coming to terms with this alienation is through their own narratives of illness—how they believe they were stricken ill, how they believe they can get better, what they fear in the course of treatment, and how they anticipate coping with their treatment and recovery, or perhaps death. These narratives are important pieces of evidence, identifying as they do the ways our health care system can better respond to suffering. Katie Patsakham affirms this perspective in her commentary when she writes that "this unique capacity of patients to share the way in which they experience illness is a defining characteristic in the practice of medicine."

It is also a defining characteristic of patient advocacy, a term we use for the way it recognizes that the very experience of being (or having been) a patient confers an authority of its own, an authority that can create a powerful base from which to advocate. Barbara Rimer references this concept in her dedication piece, which remembers Michelle Mayer, a faculty member at the UNC Gillings School of Global Public Health, and the blog Michelle maintained in the months preceding her death. In that blog, Diary of a Dying Mom, Michelle wrote of her advocacy efforts to receive better care in a complex health system. She reminded readers that she made these efforts even as she struggled with constant physical pain, and even as she maintained her commitments to being an active professional, loving wife, and devoted mother of two children.

Tiffany Christensen also embodies this authority, as is clear from her commentary in which she describes her experiences as a patient advocate. Now 36 years old and a self-described "life-long patient," Christensen was born with cystic fibrosis, weathered a double lung transplant, and now makes it her life's calling to help others make the leap to activated patient. Walking readers through her own experience, and writing in a simple, direct, and personal way, she coaches others in self-advocacy through her publications and other resources.[4,5] "I have learned that being hospitalized is not a time to relax and heal," she writes, "but rather [a time] when I must assume responsibility for steering my own health care ship. If I am too sick to stand at the helm," she continues, "I must have a friend or family member take over from me." Beverley Johnson, Marie Abraham, and Terri Shelton also represent this perspective in their commentary. They focus their work on how the practice of listening to patients and family members can inform significant change, from the redesign of hospital rooms to accommodate family member sleepovers, to the redesign of hospital gowns to ensure patients' dignity or, more radically, to policy revisions that would allow parents to attend to their children, even during emergency procedures.[6,7]

As these examples suggest, forming a vocabulary for patient or health advocacy is more than a semantic exercise. Encoded within these word choices is a philosophy of practice that has important implications when it comes time to train those within and outside the health professions. Consonant with the work of our advocate colleagues and the contents of the IOM reports, we ultimately chose to use the term *patient* in this issue of the *North Carolina Medical Journal*, and in our textbook, for the way it refers back to individual and family experience as the driver of improvements in health care. Of utmost importance in patient advocacy work are improvements that focus not only on technically excellent care or on universal access, but on care that fully incorporates the voice and point of view of the patient as the central actor in the unfolding scenarios we write about.

The Movement for Patient Safety and Health Care Quality: Further Defining a Vocabulary

Elsewhere in this issue, we write about the problem of patient safety as a subject in its own right, examining ways in which full disclosure of errors, accompanied by an apology, is likely to: help maintain trust among patients, providers, and institutions; reduce the likelihood that such errors will be repeated; and lessen the possibility of adversarial litigation. Catherine Cravens and Jo Anne Earp discuss this set of issues in more detail in their commentary in this issue of the *Journal*. In recent years, patient safety issues have helped frame the discourse on patient advocacy, so deserve a discussion here as well. Christensen herself references patient safety as a prime motivator for her own work. "In a country where between 44,000 and 98,000 people die each year from medical error, being an informed and alert advocate is not a choice but a necessity."

Christensen, of course, is drawing these data from *To Err is Human*, which captured the attention of the scientific community and the popular media with its aforementioned estimate of deaths due to preventable medical errors.[8] The report generally attributed these deaths not to the malpractice of individual physicians, but instead to widespread structural problems within health care systems. The second IOM report, *Crossing the Quality Chasm*, looked at the broader topic of health care quality, including issues of patient safety, patient experience, cost, and access to services.[9] The wider point being made here is that these watershed reports legitimized both a vocabulary and an approach to changes within health care organizations.

The *Quality Chasm* report is particularly striking in this regard, especially in its emphasis on patients. From page one, the report underscores the provision of patient-centered care as one of six fundamental reforms needed in US health care. Defined as care that is "respectful of and responsive to individual patient preferences, needs, and values, and [that] ensur[es] that patient values guide all clinical decisions,"[9] patient-centered care took its place in the report as the driver of all six reforms it supported. The Committee also set forth 10 "rules" for reforming health care systems, in which patients were featured prominently. These rules include "customizing care based on patient needs and values;" making the patient "the source of control" in decision-making; ensuring "shared knowledge and the free flow of information" between patients and providers; and creating greater "transparency."[9] Finally, the Committee named patients, along with health care organizations, purchasers, and providers, as essential participants in the drive towards change. If *To Err is Human* emphasized the importance of systems analysis in health care, *Crossing the Quality Chasm* established the patient—not hospitals and not providers—at the center of those systems.

Both IOM reports owe a debt to a philosophy of care pushed forward by patient advocates over the course of many years. As the commentary by Beverley Johnson and colleagues demonstrates, it is a philosophy undergirded by the idea that, insofar as providers respect the agency of the patients they work with, they should empower those individuals to the extent possible to participate in decisions that will affect their health and well-being.

The IOM reports have significantly shaped advocacy efforts since their publication. First, they have provided advocates with the imprimatur of the IOM *and* with the data illustrating that widespread structural problems *do* exist in the health care system. Second, the reports confirm the need to think beyond culpability of individual providers to consider system-level factors that explain variations in health care quality. Third, the IOM has given credence to a vocabulary and an approach that helps patient advocates move forward in concrete ways towards their goals. The very term *patient-centered care*, for example, (together with sister terms such as *family-centered*, *relationship-centered*, and *patient-directed care*) is gaining greater acceptance. Finally, the reports may be credited more generally with bringing awareness to issues such as the presence of structural and cost barriers, variable communication styles, questionable control over resources, and, ultimately, medical decision-making. In 2006, then Senators Clinton and Obama lent their star power to the discussion, arguing in the *New England Journal of Medicine* that improvements in patient safety should be at the center of medical liability reform.[10] These issues are central to patient advocates. That the health care system is often confusing, unpleasant, and dangerous has, in effect, been transformed from anecdotal experiences repeated by frustrated patients to a scientific knowledge base increasingly accepted by those both inside and outside the medical establishment.

Traditions of Advocacy

The patient safety movement has helped advance the agendas of those advocating for patients. Yet these gains emerge out of historical contexts that sometimes involve health professionals but just as often owe their thanks to charismatic lay people with the vision, skills, and persistence to either agitate for change from the outside or gain entrée into the medical world and collaborate from that vantage point. These traditions of advocacy are instructive, both in terms of delineating core tenets held by patient advocates and in suggesting the need for "pitching a big tent" that embraces change agents from many backgrounds and professions.

Advocacy and the Helping Professions

The legal profession has put its own stamp on patient advocacy, particularly in the realm of establishing patient rights.[3] In his commentary, Edward Connette extends this discussion, offering a "then and now" snapshot of health care coverage and how he, as a practicing attorney, has worked to help people whose health benefit plans have denied coverage for life-saving medical treatment. As he reports, significant gains have been made in this arena. Together with other reasons for these improvements, Connette cites "the development of a network of highly trained, non-attorney 'patient navigators' who typically come from nursing, medical claims processing, or insurance backgrounds." As he puts it, "they perform miracles, and they do it quickly, usually at no cost to the patient."

However the conversation does not stop with the law. As suggested by Connette, those in the helping professions of nursing and social work also have deep roots in patient advocacy,[11] as do those who offer particular kinds of care, such as mental health or palliative care, in which patients' autonomy is frequently in jeopardy.[12]

Nurses in particular practice a form of patient advocacy within the health care system, often acting as a liaison between the patient and others involved with the provision of care. In this capacity, they mediate among family members, providers, medical institutions, insurance carriers, researchers, and others. Yet others take on this role as well, including social workers, physicians, and, increasingly, family members, lay health advisors, or hired patient advocates. Regardless of their professional affiliations, all those working as advocates in clinical environments are called to practice what Baldwin has identified as the three "essential attributes" of patient advocacy: (1) valuing patients' rights to self-determination; (2) apprising patients through a combination of education and advising so that they may take full part in decision-making; and (3) interceding between patients and others, including family members and physicians, to ensure that patients' wishes are honored.[13]

In their commentary on veterans seeking health care through the Veterans Health Administration (VHA), Linda Kinsinger, Joan Van Riper, and Kristy Straits-Tröster spotlight this role and, in doing so, underscore the way hospital-based patient advocates fill a critical need. If the advocates weren't there, individual patients would suffer—critical information might not make it from one provider to another; a particular procedure might not be approved; or a patient might miss out on an opportunity to participate in a fully informed decision about his or her own treatment.

Yet as Lance Stell's commentary on clinical ethics and patient advocacy suggests, intermediaries (in this case clinical ethicists) who work to protect patient autonomy can be compromised by institutional forces (the drive towards economy and efficiency within the workplace), by more personal forces (conflicts within families over the right course of treatment), or by the fact that advocates are not always in agreement themselves over which direction to go in. Furthermore, the ethical ideals imbued during advocates' training (whether that training is in nursing, social work, philosophy, or some other discipline), while often stressing patient-centeredness as a core value, may attenuate under the immediacy of care delivery that necessitates pragmatic compromises. These challenges suggest the need on the part of hospital-based patient advocates or ethicists to maintain a delicate balance between ethically representing the patient while also maintaining collegial relationships with hospital personnel to ensure that their requests get a fair hearing. In other words, the role of a patient advocate calls on the skills of the diplomat, the inquisitiveness of the educator and problem solver, and the courage of the activist to speak up in difficult situations.

Advocacy and Palliative Care

Patient advocacy also has roots in particular areas of health care delivery, such as palliative care. As with the nursing profession, advocates in palliative care have led in the effort to legitimize and increase patients' comfort and autonomy. Leaders in the field emphasize: (1) open communication between patients and providers about care preferences; (2) the importance of cultural and spiritual dimensions of care; and (3) the need for adequate pain management.[14] Their advocacy efforts have often focused on organizational change and, indeed, have resulted in hospice programs and health care powers of attorney designed to provide comprehensive services that safeguard patients' wishes and guard their autonomy right up to the moment of death. In this model, physicians and nurses collaborate with families, religious and spiritual practitioners, volunteers, and others to minimize patients' suffering and carry out patients' wishes as they progress through this natural stage of life.[15] Palliative care advocates' success with this end-of-life care model illustrates ways in which advocates have helped redesign the organizational parameters of the health care system so patients' rights and preferences are honored in all their complexities.

In this context, Laura Hanson's commentary offers an update on disparities in how the palliative care model, as well as other forms of care, have been disseminated. As she points out, "African Americans are more than twice as likely as whites to make choices in favor of life-prolonging treatment," meaning that they are less likely to access hospice care when treatment options are exhausted. Hanson's piece underscores the degree to which the efforts of patient advocates have so far benefited some patients more than others. Yet Hanson also spotlights the work of advocates who are developing innovative ways to reach underserved populations. In her case, Hanson is testing the use of a lay health advisor model to identify African American cancer patients earlier in their illness, to involve them more fully in their care decisions, and to increase their awareness of palliative care options. Similarly, Carmen Lewis and Michael Pignone focus their advocacy efforts on health literacy, innovating ways to help *all* people grasp complex health information both out of respect for all patients' right to agency and because activated, knowledgeable patients have better health outcomes than those who simply "follow doctors' orders."[16] In their commentary, Lewis and Pignone discuss the use of decision aids as a means to increase informed decision-making in primary care.

Activism

A third realm of patient advocacy involves activists, often survivors of disease, who work to improve health care for people frequently marginalized by socially stigmatizing diseases,[17] including HIV/AIDS or, in an earlier day, breast cancer. Patient advocacy in this context is often tied to broader social movements such as gay rights, women's rights, or consumer health movements. The activist tradition in advocacy spotlights the role of the "outsider," i.e., one who may not have been trained in the helping or legal professions but who can push for change based on charisma, strong organizing skills, and a lived experience of the issues at hand.[18] The efforts of these "outsiders" in recent years have been fueled by new communication technologies like the internet that give patients and families unprecedented access to health information and the ability to share that information widely.[19]

In the case of breast cancer, patients, their family members, and survivors have helped change how clinicians, colleagues, and the public regard this once-stigmatizing disease.[20] Through their efforts, patient-provider communication is now more transparent, treatment guidelines have been modified, and employment laws have been changed.[21] Advocates' public awareness campaigns, grassroots organizing, fundraising, lobbying, and coalition building have increased access to screening and treatment services; secured funding for discovery, translation, and dissemination; and introduced patients as experts in the process of designing and conducting breast cancer research.[22] In this case, patients serve not just as the recipients of advocacy, but as the source of it as well.

In another stream of activism, many advocates focus on broader health issues relevant to minority populations. In her commentary, Florence Simán looks at health disparities among Latino immigrants living in North Carolina, directing attention to possible sources of misunderstanding between patients and providers once they have overcome considerable barriers blocking their access to care. Chloe Katz narrows that examination further in her discussion of the ways that refugee health issues may differ from those of other immigrants.

As the commentaries in this issue of the *North Carolina Medical Journal* suggest, other powerful dimensions of patient advocacy have also informed the movement. Yet nursing, palliative care, and disease-specific activism, together with the more recent focus on patient safety, can serve as a shorthand for the shared outlook and aims of this still nascent, but growing, social movement. More importantly, each of these traditions illustrate ideas central to patient advocacy: patients' right to self-determination; how changes in institutional culture can better support people who are in need of care; how greater patient participation can increase patients' investment in their own health, deepening their trust in the provider along the way; and how an advocate's place inside or outside an organization affects the methods of advocacy she chooses and the degree of social change she achieves.

Patient Advocacy as a Profession?

Several scholars have identified signs that patient or health advocacy is coalescing as a profession.[23] They cite as evidence the initiation of several graduate level advocacy training programs[b] and the proliferation of patient advocacy businesses such as Health Advocate, Inc.[c] Additional indicators include recent calls for credentialing health advocates[23] as well as an increase in survivors of disease who work within hospitals as patient representatives, establish their own nonprofits, sit on review panels, and perform other important quality improvement work. This issue of *NCMJ* features some of these types of advocates, including Nancy Davenport-Ennis, the founder and CEO of the Patient Advocacy Foundation and the National Patient Advocacy Foundation and Tiffany Christensen, author of *Sick Girl Speaks*.

At UNC Chapel Hill, our training efforts have focused on methods of advocacy that health professionals can draw on—how health educators, hospital administrators, physicians, nurses, pharmacists, social workers, and occupational therapists can blend their advocacy skills and activist inclinations with their professional roles to powerful effect. We teach skills, such as media advocacy, as discussed by Ann Houston Staples in her commentary. We focus on ways to harness new media so that, as emphasized by Adam Searing in his commentary, advocates can be alert and ready when the time is ripe to make an all-out push for major reforms. And, as highlighted in the commentary by Joseph Colletti, we look closely at varying approaches for insuring more, if not all, US citizens. We focus on these strategies recognizing that, while patient advocacy may eventually come into its own as a profession with its own standards and tenets of training, those professionals who enter this arena without a distinct career track may need to be very entrepreneurial indeed. Yet as this issue of the *NCMJ* shows, these social entrepreneurs are one of *the* nerve centers of advocacy. Without their perspective and point of view, our advocacy efforts would be drained of the legitimacy provided by their lived experience.

Our understanding of patient advocacy concepts and core issues is still evolving, as is emphasized in the piece by Melissa

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[b] Sarah Lawrence College (MA in Health Advocacy, est. 1980); University of Wisconsin (patient advocacy courses in law school for medical, nursing, and law students; Center for Patient Partnerships, est. 2000); University of Cincinnati (est. 2001); UNC at Chapel Hill (courses offered through the School of Public Health, est. 2006); and Columbia University (MA in Narrative Medicine, est. 2008).

[c] Health Advocate Inc. (http://www.healthadvocate.com) is a company that helps patients and family members navigate health care systems, from clinical to insurance issues. Personal health advocates, often registered nurses, help clients identify and secure appointments with the best doctors and hospitals for their particular conditions, help resolve insurance issues, help clients understand serious chronic conditions, and help clients and families identify additional health resources.

Gilkey and Jo Anne Earp. Each of the commentaries in this issue illuminates some aspect of patient advocacy in North Carolina, whether that means advocating for more thoughtful ways of working with immigrant or veteran populations, empowering patients with low literacy, or improving data collection and reporting methods to more easily identify and better track patterns of error in hospitals. By looking at these disparate issues through the lens of patient advocacy, we offer a better chance of working collectively to identify advocacy strategies that can be effective in many settings to remedy some of the most stubborn problems in health care. Without health care quality improvement along the lines advocated in this issue of the *North Carolina Medical Journal*, we will not achieve the aims, scope, reach, or potential that the evolving patient advocacy social movement promises, not only to its adherents, but to patients and their families everywhere. **NCMJ**

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Defining Patient Advocacy in the Post-*Quality Chasm* Era

Melissa B. Gilkey, MPH; Jo Anne L. Earp, ScD

Patient advocacy is a concept that generally refers to efforts to support patients and their interests within the context of the health care system. As discussed in the issue brief that introduces this issue of the *North Carolina Medical Journal*, a more specific or applied definition of patient advocacy is difficult to articulate, in part because the term has been used in many different ways. For example, the role of advocate is often ascribed to certain professions, especially the "helping professions" of nursing and social work.[1] Others associate patient advocacy with particular kinds of care, such as mental health or palliative care, in which vulnerable patients' autonomy may be in jeopardy.[2] A third use of patient advocacy is to denote the work of policymakers, legal professionals, and activists who work to improve health care for people marginalized by socially stigmatizing diseases such as HIV.[3] Given the variety of contexts in which the concept is used, research can help us better explicate *patient advocacy*, a task necessary for advancing both scholarly and applied efforts to improve health care quality.[4]

Our research goal was to explore the concept of patient advocacy as defined by those known as leaders in advocacy practice. Specifically, we wished to gain a better understanding of the personal and professional roles associated with patient advocacy as well as its primary goals, methods, rewards, and challenges. Toward this end, we surveyed a national sample of leaders in patient advocacy practice in 2005, using a confidential, online questionnaire known as the University of North Carolina Patient Advocacy Survey.[a]

Participants

We constructed a sampling frame of 203 patient advocacy leaders with the goal of recruiting a purposive, non-probability sample of respondents from a wide variety of advocacy interests and backgrounds. First, we included 161 invitees of the University of North Carolina Patient Advocacy Summit. This national conference, held in Chapel Hill in 2003 and 2005, brought together advocacy leaders from many sectors of the US health care system.[5] Second, we asked that each invitee recommend others for the survey whose perspective on patient advocacy was believed to be important. In this way, we obtained an additional 42 names with viable email addresses.

> *"…a specific definition of* patient advocacy *is difficult to articulate, in part because the term has been used in many different ways."*

Questionnaire Development and Administration

We developed a self-administered, online questionnaire to investigate the concept of patient advocacy. The 35-item survey contained both closed- and open-ended questions based on five dimensions of interest: (1) personal and professional roles associated with patient advocacy; (2) its primary goals and methods; (3) important next steps; (4) its definition; and (5) rewards and challenges associated with its practice. Additional items assessed the demographic characteristics of respondents. The survey took approximately 20 minutes to complete and was pretested by seven people with varying levels of health-related knowledge and experience.

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[a] The North Carolina Patient Advocacy Survey can be found in its entirety online at http://www.ncmedicaljournal.com.

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We invited each participant via email to complete the web-based questionnaire. Those who did not respond were emailed reminders 7 and 20 days after the original invitation. A drawing for a $100 gift certificate to an internet retailer was offered as incentive for participation. The University of North Carolina School of Public Health Institutional Review Board approved this unfunded study.

Analysis

To analyze quantitative data, we used the Statistical Package for Social Sciences (SPSS) software. First, we derived overall frequencies for each item. Second, for summary purposes, all items with Likert-style response options were collapsed into "high" and "low" categories. Qualitative data were coded according to our five dimensions of interest and analyzed thematically for areas of consensus and divergence.

Respondents

Of 203 possible respondents, 112 accessed the survey site and gave consent, for an overall response rate of 55%. Respondents came from many backgrounds with the greatest number designating the fields of public health (20.2%) and medicine (19.3%) (see Table 1). The majority of respondents were female (74%), white (92%), and held graduate-level degrees (86%).

In terms of advocacy experience, most respondents (73%) reported having worked on health-related advocacy issues for nine or more years. Respondents reported practicing health-related advocacy in various contexts (see Table 2) with their primary advocacy interest spanning 13 different areas (see Table 3). Primary reasons for becoming involved in health-related advocacy were similarly diverse, with about one-quarter (26%) indicating that a family member or friend's experience as a patient motivated them.

Table 1.
Percentage of Patient Advocacy Survey Respondents by Professional Background[b]

	Percent (n)
Public health	20.2 (22)
Medicine	19.3 (21)
Law	9.2 (10)
Humanities	5.5 (6)
Education	4.6 (5)
Journalism	3.7 (4)
Nursing	3.7 (4)
Business	2.8 (3)
Social work	2.8 (3)
Government	2.8 (3)
Other	25.7 (28)
Total	100 (109)

Table 2.
Percentage of Patient Advocacy Survey Respondents Who Practice Advocacy in Various Contexts[b]

	Percent (n)
Member or leader of a nonprofit organization	28.4 (31)
Researcher or evaluator of health care services	18.3 (20)
Member or leader of an academic institution	13.8 (15)
Provider of health care services	12.8 (14)
Member or leader of a governmental agency	2.8 (3)
Other	17.4 (19)
Not applicable	6.4 (7)
Total	100 (109)

Advocacy Roles

Survey respondents perceived a number of different groups to be directly and indirectly important to patient advocacy efforts:

- When asked which of seven groups "often" or "sometimes" take on the role of patient advocate, three-quarters or more of respondents indicated patients themselves (75%), family members or friends (86%), nurses (81%), social workers (86%), and hospital patient representatives (77%). Almost half (51%) indicated that physicians do so.
- The majority of respondents wished all these groups were more active in advocacy efforts with over three-quarters saying they would like to see patients themselves (82%) and physicians (84%) take more of a role in patient advocacy.
- The majority of respondents also felt that a "big role" or "somewhat of a role" in health care advocacy is played by leaders of nonprofit organizations (83%), educators of patient advocates (93%), and activists and grassroots organizers (96%).

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[b] Data on three respondents were not provided.

- Over two-thirds of the respondents wished to see hospital administrators (75%) and legislators (68%) take more of a role in patient advocacy initiatives.

Advocacy Goals, Methods, and Next Steps

When we asked respondents to rate the relevance of various advocacy goals, the vast majority named as "very relevant" the goals of improved patient-provider communication (94%), patient-centered care (92%), quality improvement and patient safety (90%), and increased access to care (85%).

In terms of advocacy methods, almost two-thirds of respondents (63%) reported that patient/consumer education is a method "often" used by patient advocates. In terms of methods that should be used more often than they currently are, almost three-quarters indicated organizational change in hospitals (73%) and provider education or curriculum reform (72%).

In terms of important "next steps" for patient advocacy, over half of the respondents assigned a "high priority" rating to coordinating advocacy efforts more effectively (67%), raising public awareness about advocacy issues (66%), and training more advocates/training advocates more effectively (58%).

Table 3.
Percentage of Patient Advocacy Survey Respondents by Their Primary Advocacy Interest[c]

	Percent (n)
Education of advocates	13.0 (14)
Consumer health advocacy	12.0 (13)
Advocacy by patients' family or friends	9.3 (10)
Advocacy by clinicians	9.3 (10)
Research in advocacy related topics	9.3 (10)
Hospital or organizational change	6.5 (7)
Advocacy by patients themselves	5.6 (6)
Legislation or policymaking	5.6 (6)
E-health or internet advocacy	2.8 (3)
Inclusion of advocates in the planning of research	1.9 (2)
Grassroots organizing	0.9 (1)
Legal advocacy	0.9 (1)
Media advocacy	0.9 (1)
Other interest	6.5 (7)
No single major interest	15.7 (17)
Total	100 (108)

Definitions of Patient Advocacy

Qualitative data indicated that respondents defined patient advocacy along the four themes of: (1) taking a multipronged approach; (2) empowering patients; (3) creating a culture of patient-centeredness; and (4) improving health care quality. Each of these themes is illustrated with a representative quotation below.

(1) Taking a multi-level approach that includes both individual- and systems-level advocacy.

> *"Patient advocacy is supporting and empowering patients to make informed decisions, navigate the system to get the health care they need, build strong partnerships with providers while working towards system improvement to support patient-centered care. Patient advocates are dedicated first and foremost to the well-being of the patients they serve."*
>
> — Educator of advocates

(2) Empowering or activating patients by facilitating patients' education, their greater involvement in decision-making, and their ability to more easily navigate the health care system.

> *"Efforts to ensure that patients have the information and the self-determination they need so that patient needs are forefront in decisions about patient care."*
>
> — Health services researcher

(3) Changing hospital and provider culture to be more patient-centered.

> *"Patient advocacy is the bilateral appreciation that the focus of medical intervention should be 'patient-centered.' [Patient-centeredness] includes the sharing of decision-making, risks, cost effectiveness, treatment regimens, goals, and expectations. [Patient advocacy] must be implemented with an appreciation of the individual patient and physician in the global context of health care."*
>
> — Nonprofit leader

(4) Improving health care quality, particularly in regard to patient safety and access to care.

> *"Assisting people (either as case advocacy on behalf of individuals or class advocacy on behalf of a group) with the process of receiving health care, maximizing their health, and assuring that all people have access to safe and comprehensive health care."*
>
> — Health care service provider

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[c] Data on four respondents were not provided.

Rewards and Challenges

The rewards associated with practicing patient advocacy were most often described in terms of satisfaction derived from helping others, improving provider practice as well as health systems more broadly, and improving patients' health outcomes. For example, in response to the question about rewards, one respondent wrote:

> *"Witnessing and hearing one-on-one success stories from patients' perspectives. Observing measurable changes in policies and laws that create a more empowering environment for those in need of health care services."*
>
> — Public health researcher

In terms of challenges, respondents noted the slow pace of change, the emotional and frustrating nature of the work, an antagonistic attitude among some providers, and the lack of funding for advocacy practice and research.

> *"The deep-seated ambivalence, if not outright hostility, of providers to the notion that patients are more important than they are and should ultimately be more powerful than providers in determining health care decisions."*
>
> — Researcher of consumer health advocacy

> *"The gap between information and real change in provider practices that are obviously deficient and producing systemic inequalities in care, compounded by the rigidity of current funding streams and federal regulations for blending or modifying funding to increase provider coordination of care."*
>
> — Provider of health care services

Our data suggest that survey respondents define the concept of patient advocacy using the language of health care quality improvement. Likely reflecting the influence of the Institute of Medicine of the National Academies' (IOM) *Crossing the Quality Chasm* report,[6] many respondents identified patient-centered care, with its dual aims of improved patient-provider communication and increased patient safety, as the ultimate goals of patient advocacy. Like the IOM, survey respondents emphasized the importance of a multipronged approach aimed at helping individual patients navigate the system while at the same time working to address the system-level problems that create the need for advocacy in the first place.

In terms of advocacy roles, survey respondents associated patient advocacy practice with many different groups, including patients' family members and friends, the helping professions of social work and nursing, nonprofit organizations, and those involved in activism and grassroots organizing. Respondents wished to see two central figures of the medical encounter, patients and physicians, take more of a role in advocacy, but they also focused on calling for system-level change. Quantitative data indicated that they would like to see hospital administrators and legislators take more of a role in patient advocacy, while qualitative data emphasized the importance of organizational restructuring and policymaking to bring about change.

Despite differing professional backgrounds and advocacy foci, respondents tended to define the rewards and challenges of advocacy practice in similar terms. While advocates enjoyed the opportunity to help patients and improve health care systems, they expressed frustration about encountering opposition to their perspective, as well as about the slow pace of change and lack of funding for their work.

Our data suggest a fair degree of consensus among a diverse sample of respondents in this field as to the primary goals of patient advocacy. Both quantitative and qualitative data indicate that patient-centeredness, patient safety, improved patient-provider communication, and, to a lesser extent, access to care are of concern to patient advocates. Given these shared goals, the time would seem ripe for fostering a greater degree of collaboration among advocates who have traditionally been divided along lines of population, disease, and professional interests. The fact that respondents most often prioritized the coordination of advocacy efforts as an important next step lends further evidence to this claim. By collaborating more closely, patient advocates could potentially strengthen their chances for success while at the same time mitigating some of the sense of frustration that seems to attend such work.

This exploratory study provides insight into how patient advocacy leaders conceptualize their work. With the majority of our participants claiming more than nine years in patient advocacy, our data suggest that we drew from a group of experienced leaders. Nevertheless, it is important to note that our sample size was small and, furthermore, the experiences and perceptions of advocacy "leaders" who were targeted for this survey likely differ from those of day-to-day practitioners. Additionally, about half our survey respondents were culled from two conferences we hosted, and their answers may reflect discussions they had with us and with each other. Finally, although our data suggest that we were successful in recruiting respondents from a broad range of professional backgrounds and advocacy foci, it may be that our snowball sample failed to tap areas of advocacy unknown to us or to conference participants.

Despite these limitations, we believe our preliminary findings suggest areas of consensus as to the goals of patient advocacy that we, in North Carolina, are well-positioned to pursue. In terms of leadership, we may look to a pragmatist but forward-thinking legislature and executive branch as well as to our many committed and experienced advocacy groups. By promoting networking and collaboration among these and other health care and political leaders, innovative practitioners, and committed patients, we have the potential to advance the mutually reinforcing goals of increasing patient-centered care, enhancing patient safety, improving patient-provider communication, and expanding access to care. **NCMJ**

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Patient- and Family-Centered Care:
Partnerships for Quality and Safety

Beverley H. Johnson; Marie R. Abraham, MA; Terri L. Shelton, PhD

Core Concepts of Patient- and Family-Centered Care

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered care also offers a framework within which to begin examining policies, programs, and practices and for hospitals, ambulatory practices, and agencies that choose to do so, to begin on a journey to transform organizational health care culture.

As defined by the Institute for Family-Centered Care, patient- and family-centered care is guided by the following four concepts:[1]

- ***Dignity and respect.*** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- ***Information sharing.*** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- ***Participation.*** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- ***Collaboration.*** Patients and families are included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; health care facility design; and professional education. Patients and families also collaborate in the delivery of care.

Why Is Patient- and Family-Centered Care Important?

Because of its focus on participation and collaboration, patient- and family-centered care means working *with* patients and families rather than doing *to* and *for* them. It makes families, patients, and health providers partners in care. In patient- and family-centered care, patients define who their family members are and how they will be involved in care and decision-making. Partnerships with families are essential because for the patient, the families are the constant—the link across different settings. Their presence for ambulatory care appointments, hospital stays, and especially during the planning for transitions in care can help ensure quality and safety.

> *"Because of its focus on participation and collaboration, patient- and family-centered care means working* with *patients and families rather than doing* to *and* for *them."*

The basic tenets of patient- and family-centered care (e.g., respectful partnerships, open communication, shared decision-making, and strength-based approaches) often run counter to the ways in which health care has traditionally been taught and practiced. More recently, patient- and family-centered concepts and strategies are being incorporated into health policy legislation;[2] respected national organizations are issuing policy statements and publications that support patient- and family-centered practice;[3] and funding agencies are encouraging researchers to study patient- and family-centered policies

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and practices and include patients and families in the research process itself.[4,5]

An accumulating body of research demonstrates that patient- and family-centered care benefits everyone involved —patients, families, health care providers, and payers. Moreover, its benefits are substantial. Patient- and family-centered care is increasingly linked to improved health outcomes; lower health care costs; more effective allocation of resources; reduced medical errors and litigation; greater patient, family, and professional satisfaction; increased patient/family self-efficacy/advocacy; and improved medical/health education.[6-14]

Examples of Emerging Best Practices in Patient- and Family-Centered Care

Ambulatory medical practices, hospitals, and health systems today are increasingly integrating patient- and family-centered approaches and concepts into their daily operations, as demonstrated by the following examples:

- Patients and families are supported and encouraged in being essential members of the health care team across the continuum of care.
- Collaborative self-management support, an approach where patients and families are encouraged and supported in setting goals and action plans, has become the standard for managing chronic conditions in ambulatory settings.
- Families are no longer viewed as visitors and signs are no longer posted on hospital walls that indicate the hours during which families may be with a loved one. They are involved as allies for quality and safety in clinics, at the bedside, and in the community.
- Rounds are conducted in a manner that facilitates the involvement of the patient and, according to patient preference, the family.
- Nursing change of shift report is conducted at the bedside with the patient and family.
- Charting and documentation systems in primary care, ambulatory settings, and hospitals capture the goals, priorities, preferences, concerns, and observations of patients and families and ensure patient, family, and clinician access to information.
- Patients and families are involved in transition and discharge planning.
- Patient and family advisors are partners for change and improvement in health care settings and in institutions educating future physicians. They serve as family faculty in academic medical centers and schools of medicine, where they play key roles in educating students, residents, and fellows.
- More and more hospitals are establishing patient and family advisory councils and involving these advisors in a variety of quality improvement and patient safety initiatives.

Growing National and State Momentum for Patient- and Family-Centered Care

As individual ambulatory practices, hospitals, and health systems continue to advance the practice of patient- and family-centered care, there is also tremendous momentum at national and state levels. As outlined below, momentum is building for partnerships with patients and families not only as active participants in care and health care decision-making but also as advisors and partners in teaching, quality improvement, and redesigning our health care system. Increasingly, these examples demonstrate the evolution from patient- and family-centered as a "nice thing to do" to a recognition that delivering care in this manner is integrally tied to larger issues of quality and safety.

National Momentum

In 2004, the American Hospital Association, together with the Institute for Family-Centered Care, developed tools that define patient- and family-centered care and how leaders, trustees, and senior executives can foster this approach to care.[15] This partnership illustrates how the principles of patient- and family-centered care are increasingly linked with quality care. For example, the prestigious AHA McKesson Quest for Quality Prize for hospitals has integrated partnerships with patients and families throughout the award criteria, encouraging patient and family participation in rounds, providing access to their medical records, and changing the concept of families as visitors.[16] The award recognizes hospital leadership for aligning the agendas for quality, safety, and patient- and family-centered care.

One of the Joint Commission's patient safety goals specifies involving the patient as a patient safety strategy. The Joint Commission has developed several resources that describe partnerships with patients and their families and offer strategies for moving forward with patient- and family-centered care.[17,18]

Similarly, patient and family engagement is the first of six priorities in the National Priorities Partnership Action Agenda to Improve Health Care, a report funded by the Robert Wood Johnson Foundation and developed and endorsed by the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Agency for Healthcare Research and Quality, the Institute of Medicine, the Institute for Healthcare Improvement, the Joint Commission, National Quality Forum, National Committee for Quality Assurance, the National Business Group on Health, the National Governors' Association, and 18 other organizations.[19] The core concepts of patient- and family-centered care provide a framework and strategies to achieve these priorities.

While the principles are clearly evident in the tenets of the medical home for children, efforts are underway nationally to bring about major change in *adult* primary care through the Joint Principles for the Patient-Centered Medical Home.[20] These principles, all of which are closely tied to those of patient- and family-centered care, include the following:

Starting Life with Coordinated Care

Sarah Verbiest, DrPH, MSW, MPH

The Center for Maternal and Infant Health's Care Coordination Program is an interdisciplinary model designed by the UNC Departments of Pediatrics and OB/GYN in partnership with the School of Medicine and the UNC Health Care System. The program was launched in 1999 with funding support from The Duke Endowment and the Kate B. Reynolds Foundation. Since that time, the Center has provided patient-centered care for over 4,500 high-risk pregnant mothers and infants from 80 counties across North Carolina. The Center takes a family-centric approach that brings together a wide range of medical expertise in one location, coordinates care with a focus on the mother-baby-family unit, and maintains a continuous channel of communication among health care providers (both those at UNC and pediatricians/obstetricians in the community). The team supports families through the highly emotional and complex world of prenatal/infant diagnosis, prognosis, treatments, and specialty services. A primary goal of the program is to help parents learn how to navigate the health care system and become advocates for themselves and their babies.

Each patient has a care coordinator who is present with families from diagnosis through major surgeries and often through the baby's first year of life. The coordination team consists of nurses, a nurse midwife, and bilingual (Spanish/English) clinical social workers. Coordinators attend key health care visits and consultations with the patients, helping them generate questions to ask their provider before the encounter and checking afterwards to be sure they have a good understanding of what transpired. They share information about the family, their social situation, needs, and wishes with the interdisciplinary team as part of a collaborative effort to develop care plans. Coordinators also provide patients with education about their baby's condition, links to local community groups, appointments with multiple specialty providers on the same day to create one stop services, referrals to clergy and mental health services, transportation, food, early intervention, home health agencies, and support groups. Having bilingual coordinators is essential to the program as Latino families face additional language and cultural barriers.

Additionally, the Center supports a perinatal palliative care program for families who have received a terminal fetal diagnosis. This service focuses on helping families play a leadership role in developing their birth plan, making decisions in advance on behalf of their baby, and preparing for the loss. The Center team also offers care coordination for pregnant mothers who are transported to UNC due to emergency medical conditions. The Center's newest program provides care to mothers who have infants in the intensive care nursery. These mothers have many unmet health, social, and emotional needs that impact their own well-being as well as their ability to care for their baby.

While each family faces its own unique set of challenges and circumstances, they share a deep love for their children. The Center team is united in their effort to work in partnership with families to encourage and support their transition into being parents of very special babies. To learn more about the work of the Center for Maternal and Infant Health please go to http://www.mombaby.org or call 919.843.7865.

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- The care-planning process is driven by a compassionate, robust partnership between physicians, patients, and the patient's family.
- Patients participate actively in decision-making.
- Care is coordinated and/or integrated across all elements of the health care system (e.g., subspecialty care clinics, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services) in a culturally and linguistically appropriate way.
- Information technology is utilized to support optimal patient care, performance measurement, patient education, and enhanced communication.
- Patients and families participate in quality improvement at the practice level.

An excellent summary of this national groundswell can be found in the 2008 publication of the Institute for Family-Centered Care, *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*.[21] The publication synthesizes results of an invitational expert panel convened by the Institute for Family-Centered Care in collaboration with the Institute for Healthcare Improvement. The report's recommendations are illustrated by examples drawn from health facilities and other organizations that have made exemplary progress in partnering with patients and families. The expert meeting and report were funded by the Robert Wood Johnson Foundation and the California HealthCare Foundation.

State Level Momentum

Action at the state legislative level has also been noteworthy in recent years. For example, in 2008 the state of Massachusetts enacted legislation stipulating that every hospital in Massachusetts must have a patient and family advisory council and a process established for patients or families to call a rapid response team if there are concerns that the patient's condition is deteriorating.

Blue Cross and Blue Shield of Massachusetts, a major payer for health care in that state, has created an annual $100,000 industry best-practice award. It presented the Dana-Farber Cancer Institute with last year's award for its commitment to patient- and family-centered care and to partnerships with patients and families. Patients and family advisors serve on 92 organizational committees at Dana-Farber.

Since 2002, Minnesota has had a statewide collaborative to develop pediatric medical homes. From the beginning, primary care physicians and practices have partnered with families in this quality improvement initiative. In 2008, the Minnesota legislature passed legislation creating health care homes and stipulating that the standards for health care homes must be developed collaboratively with patients and their advocates and support the active participation of the patient and family in decision-making and in developing care plans. A consumer advisory group is participating in developing these standards.

Momentum for Family-Centered Care in North Carolina

University Health Systems of Eastern North Carolina, Greenville, North Carolina

University Health Systems of Eastern Carolina (UHS) is a regional health system serving 29 counties in eastern North Carolina. UHS includes Pitt County Memorial Hospital (PCMH), several community hospitals, physician practices, home health, and other independently operated health services. PCMH, an 861-bed tertiary care center, is the flagship hospital of UHS and serves as the teaching hospital for the Brody School of Medicine at East Carolina University.

Significant efforts to advance patient- and family-centered care at PCMH began in the late 90s. Many successes continue to be realized in Women's Services, the Children's Hospital, and in the Regional Rehabilitation Center. This progress and success, while valuable for these service lines, proved ineffective in advancing a patient- and family-centered culture throughout the organization. For patients and families utilizing multiple service lines in the organization, this had the potential to create a sense of inconsistency in their experience of care.

Over the past 18 months, multiple strategies have successfully utilized to advance the practice of patient- and family-centered care with the ultimate goal of transforming organizational culture within PCMH and throughout UHS. Recognizing that leadership was key, initial efforts concentrated on building and enhancing support from the executive team, the Board of Trustees, medical staff, and senior leadership. Patient- and family-centered concepts and strategies have been integrated within UHS through its strategic and quality plans. A new office of Patient and Family Experience with a full-time director has been created. A basic tenet of the five-year quality plan is that "quality and safety work is patient- and family-centered."

At UHS, patients and their families are no longer viewed as visitors but as partners in health care. At every point of contact, the message is communicated that patients and families are a part of the team. The hospital's new patient handbook reinforces the message that patients and families are not passive recipients of care, but allies for quality and safety. Patient and family advisors, called Family of Care Associates, are being integrated across the system including membership on interview teams for hospitalist candidates, editorial review committees for patient and family education, and on the development of transparency tools for quality and safety measures.

Perhaps the most significant sign of progress is the change in the hospital's restrictive visitation policy. Early in 2009, the four intensive care units (surgery, trauma, medicine, and neurology) at Pitt County Memorial Hospital and the East Carolina Heart Institute changed the rigid visiting policies to flexible guidelines that support family presence and participation. To garner support at the staff level for this significant change in practice, over 160 staff champions are providing education for colleagues, recruiting patient and family advisors, and working together to identify opportunities to maximize quality, safety, and the experience of care at UHS. To assure the comfort and safety of patients in the East Carolina Heart Institute, staff conduct regular "glitch" rounds with patient and family advisors to proactively address safety concerns.

With commitment to transparency, safety, and quality improvement, information about central line infections and ventilated associated pneumonia is posted on the doors at the entrance to the ICU used by patients, families, and visitors. Patient and family advisors were involved in the development of this communication and in providing information to patients and families about how they can assist in preventing these infections.

Perinatal Quality Collaborative of North Carolina

The Perinatal Quality Collaborative of North Carolina (PQCNC) was formed in 2007.[22] Initially the Collaborative convened providers, families, payers, state agencies, legislators, non-governmental organizations, and hospitals, guided by the African proverb "to go fast, go alone, to go far, go together." All 29 neonatal intensive care units (NICUs) in the state are working together to implement an online survey to gather perceptions of parents. In partnership with William E. Edwards, section chief for neonatology at Dartmouth Hitchcock Medical Center, the units will launch the first formal survey that will gauge readiness for discharge and will begin to collect and use the voice of the parents to improve the discharge process for every family and baby who begin their journey in a NICU. Multidisciplinary teams that include parents are finalizing the spring 2009 launch in each setting.

The PQCNC vision is to generate the greatest possible value in perinatal health in North Carolina. PQCNC is committed to the dissemination of best quality practices and the optimization of health resources in a manner that is fully family-centered. In determining what role families might desire in this process, PQCNC convened two statewide family meetings, attended by parents who have had children in the NICU and family support specialists. The goal was to provide family members and support specialists the opportunity to meet, discuss critical issues, and advise PQCNC on how the family voice should be incorporated in the organization.

The message was clear—family members did not want to be part of a "family committee." They wanted to be represented at all levels of the organization and have a voice in the statewide and local direction of PQCNC. As a result, families will have active roles in projects within NICUs and will serve on local perinatal quality improvement teams. In addition, parents are serving on the PQCNC leadership team that guides the development of the organization and new initiatives. Integrating the family perspective at all levels of the organization allows PQCNC to think broadly about perinatal quality improvement and to work toward the organization's goal to make North Carolina the best place to be born. This action-oriented group is committed to improving outcomes, improving the experience of the family, and getting the best value for each health care dollar spent.

Moving Forward in North Carolina

The state of North Carolina is well positioned to support expanded partnerships among physicians and other health care professionals, community and state leaders, and patient and family advisors to continue building a system of care that is patient- and family-centered and enhances outcomes, quality, safety, and cost effectiveness. Ongoing initiatives in the state such as developing the medical home and redesigning primary care, expanding health care facilities, integrating patient- and family-centered concepts into graduate and undergraduate medical education, and health services research provide timely opportunities as does the state's record in incorporating family-centered care principles in children's mental health and most recently in adolescent substance abuse and juvenile justice. Other states have shown that engaging policymakers supports the process of change toward a more patient- and family-centered system of care. Partnerships with patient and family advisors, as exemplified in this commentary, are essential to building bridges among clinicians in hospitals, community programs and practices, and with policymakers at all levels within the state in order to achieve quality outcomes for all. **NCMJ**

Table 1.
Tools to Get Started

In addition to the references below, the following tools available from the Institute for Family-Centered Care will be helpful to anyone interested in moving forward with patient- and family-centered care.

Advancing the Practice of Patient- and Family-Centered Ambulatory Care: How to Get Started
http://familycenteredcare.org/pdf/GettingStarted-AmbulatoryCare.pdf

Advancing the Practice of Patient- and Family-Centered Care: How to Get Started (In Hospitals)
http://familycenteredcare.org/pdf/getting-started.pdf

Compendium of bibliographies/supporting evidence
http://familycenteredcare.org/advance/supporting.html

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Clinical Ethics and Patient Advocacy

Lance K. Stell, PhD

Clinical ethics is a practical discipline that seeks reasonable resolution of value-based conflict and uncertainty in patient care.[1] *Practical* implies a focus on specific, manageable problems and identifying and pursuing what's workable. This means avoiding useless distractions such as going off on a tangent that no problem can be fixed until all the chronic problems in the American health care system are resolved. Reasonable resolution rules out reliance on categorical absolutes, such as "the hospital is always right," "the doctor is always right," "the nurse is always right," "the patient (or family) is always right," or "the law is always right." Hospital administrators disagree with each other. Policies and consensus statements require interpretation. Doctors disagree about what should be done, as do nurses and other providers. Family members disagree with each other and with their sick or injured loved one about plans of care. Statutes and case law vary by jurisdiction. Lawyers and judges disagree about what authority should control their arguments and interpretations. Sometimes one or another of these seems mostly right, but usually not categorically. Uncertainty and conflict impose delay, an enemy of timely decision-making in patient care. The challenge for practitioners of clinical ethics is to help find a reasonable way through these difficulties. Reasonable resolution affirmatively presupposes:

- Having good clinical information.
- Understanding the answers to questions such as: What is the patient's diagnosis and current condition? What is his prognosis for recovery to his pre-morbid state or for survival? What are the goals of care? With what probability will the current plan of care achieve them? How long will it take to judge the plan a success or failure? If the care plan fails, should the goals of care be modified? If so, what options are available for pursuing them?
- Impartially taking into account the rights and responsibilities of those involved in a conflict as customarily understood.
- Promoting candid communication and trust between decision-making partners.
- Working in good faith and in a spirit of compromise.

Customary understandings of patients' rights and care providers' responsibilities necessarily are imperfect, and sometimes contradictory, but they roughly circumscribe the range of options among which reasonable ones must be found. The medical, surgical, and nursing professions have promulgated ethical opinions on a broad range of practice issues, many of which are readily available on the internet. The hospital has long been a venue for providing in-patient care, and all hospitals have policies to guide relations between it and the professionals who provide services to patients. Federal and state statutes and case law provide additional standards that must be considered. All of these are normative resources when addressing apparently novel conflicts. The practitioner of clinical ethics cannot make useful suggestions for resolving conflict and uncertainty in ignorance of these judgment-guiding resources.

> *"Clinical ethics is a practical discipline that seeks reasonable resolution of value-based conflict and uncertainty in patient care."*

An innovation in organ procurement protocols for donation after cardiac death (DCD), which are now mandatory for medical centers that perform transplants, has garnered attention from practitioners of clinical ethics. These protocols provide for controlled withdrawal of mechanical ventilation from properly consented organ donors whose heart stops beating in the operating room. They also provide for using opioid medications to treat the dying donor's apparent distress. The protocols anticipate that the properly-selected donors will die

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from cardiac arrest within a predictable timeframe, normally within 90 minutes from withdrawal of the ventilator and extubation. And, of course, it is further provided that resuscitation shall not be attempted when cardiac arrest occurs.

For operating room personnel unaccustomed to a planned provocation of cardiac arrest and a passive response to it, this innovation in organ procurement caused considerable discomfort. Because of the vigilance of anesthesiologists and surgeons, intraoperative deaths have been dramatically reduced. In effect, patients are monitored and resuscitated continuously while in the operating room. Cardiac arrest is treated reflexively and aggressively.[2-4] The idea of standing by during an arrest, of not treating it, is outside the experience of operating room personnel. To some, the DCD protocol seemed indistinguishable from active euthanasia, and they have voiced their strong objections.[5] Yet customary understandings of patient rights in the United States include the right to forgo CPR, to have life-sustaining treatment discontinued, the right to receive medication sufficient to forestall associated distress, and the right to donate organs after death. Our pluralistic society also includes a customary understanding that health care workers should not to be compelled to participate in procedures to which they object on ethical grounds.

Practitioners of clinical ethics have addressed this value-based conflict with in-service education to review current understandings of patient rights and surrogate decision-making at the end of life. Practitioners of palliative medicine who regularly provide comfort care for dying patients have provided a practical perspective regarding how opioids are managed in such circumstances. This educational exercise put objecting operating room personnel in a better position to consider whether their discomfort with the new protocol resulted from unfamiliarity with DCD procedures or from more profound ethical considerations.

To avoid offensive coercing of those with lingering doubts, assurance is given that they will not be compelled to participate in activities to which they have abiding objections. Some are reassured, but not all. Schedule adjustments and transfers allow respect for sturdy dissenters. Whether their unrelieved discomfort is genuinely ethical is not further explored. Relieving providers' mental distress is important. Patients and the hospital have an interest that the service of operating room personnel not be grudging.

Resolution of value-based conflict is rarely perfect or exclusively correct. *Reasonable* implies that "best" and "better" must not be adversaries of "acceptable" and "good enough." For the question of whether DCD is really euthanasia or not, clinical ethics defers to the disciplines of bioethics, theology, and philosophy.

The Scope of Clinical Ethics

Clinical ethics finds practical application in three characteristic activities:

- Advising hospital administration or medical staff on patient rights policies. For example:
  - Whether and how to recognize the validity of so-called "portable no-CPR orders" when signed by physicians not on the hospital's medical staff or by practitioners whose privileges would not have included writing Do Not Resuscitate (DNR) orders, even if on staff.
  - Whether a patient's hospital DNR should be automatically suspended in the perioperative period (for a palliative operation).
  - Crafting a fair procedure on how to respond to patient (or family) demands for specific treatments the attending physician has not offered and refuses to offer.
  - How to discharge the obligation to disclose errors both when harm results and when it does not.

- Educating the hospital's health care professionals about their ethical obligations in patient care under public policies such as the Patient Self-Determination Act (PSDA), the Emergency Treatment and Active Labor Act (EMTALA), the Health Insurance Portability and Accountability Act (HIPAA), and North Carolina's Natural Death Act (NDA). For example:
  - Whether physicians who have properly discharged patients from their outpatient practices for outrageous, disruptive, or even violent behavior should nevertheless take care of those very same patients when summoned to the hospital, in an on-call capacity, by an emergency physician.
  - What confidential health information should be shared with a surrogate to enable informed consent discussions on the patient's behalf.
  - How a physician should determine whether a patient's condition is terminal and incurable, what qualifies as extraordinary means, or whether living wills executed outside the state should be respected.

- Consulting on cases involving conflict over the care of individual patients. For example:
  - Should an indwelling implantable cardiac defibrillator (ICD) be disabled at the request of a terminally ill patient when the physician believes, to a high degree of medical certainty, that a lethal arrhythmia will occur as a result but recognizes that a functioning ICD will interfere with the patient's no-CPR order?
  - Should a physician allow a patient-designated surrogate decision-maker to reverse the patient's specific, documented prior choices regarding no CPR and no non-oral nutritional support?
  - May a well-informed patient demand amputation of a traumatically injured limb despite his surgeon's belief that it is unethical to amputate a limb he has determined to be salvageable albeit one with impaired function?

- Does equality of basic health care rights imply that a never-competent patient has the same right (exercised on her behalf by a surrogate) as a competent patient to refuse a feeding tube?
- Does a pregnant adult trauma victim have the right to jeopardize her 20-week old fetus's life as well as her own life by refusing a blood transfusion on religious grounds?
- Is it unethical for a physician to perform an elective caesarean section at a patient's request when the surgeon agrees that the patient has reasonably determined that the risks of vaginal delivery vs. C-section delivery in her own case are roughly equal? Does respecting patient self-determination mean that the patient should get to choose C-section despite the fact there are no medical indications for it?

Ethics Committees

Clinical ethics has been a focus of discussion since *In re Quinlan* (1976)[6] when the New Jersey Supreme Court endorsed the idea that value-based disputes over a patient's care that arise in the hospital (i.e., whether or not it is permissible to honor a guardian's request to withdraw a ventilator from a patient who is non-terminal but in a persistent vegetative state) should be addressed within the hospital by an interdisciplinary consultative process (an ethics committee) rather than in a court of law.

At the time of the *Quinlan* decision, few hospitals had ethics committees. Clinical ethics was an informal discipline, variously practiced on an *ad hoc*, part-time basis by hospital chaplains, social workers, hospital legal counsel, risk managers, nurse managers, medical directors of intensive care units, and medical executive committee members. These health care professionals probably did not think of themselves as practitioners of clinical ethics. Nor were they listed in the hospital directory under "ethics." Rather, they had acquired personal reputations as the "go to" people to reliably, but most of all quietly, resolve value-based uncertainty and conflict in the hospital. In other words, *valued-based uncertainty and conflict over patient care in the hospital creates an informal market for ethics advice*. Every hospital has long had one or more providers of the service, irrespective that the service has not been dubbed "clinical ethics" nor its practitioners designated as "clinical ethicists."

Ethics committees (usually organized with subcommittees for policy, education, and consultation) have rapidly proliferated since *Quinlan*. Some states require hospitals to have them by statute (e.g., Maryland and Hawaii). The Joint Commission on Accreditation of Healthcare Organizations, by demanding a mechanism for addressing value-based conflicts in patient care that arise within the institution, effectively requires hospitals to have an ethics committee or an ethics consultation service. Today, virtually all hospitals and many long-term care facilities have ethics committees of some kind.

By establishing an ethics committee, a hospital openly acknowledges the possibility of having in-house value-based conflicts over patient care. However challenges exist in implementing effective ethics committees. Indeed, ethics committees in most hospitals meet infrequently and rarely get consulted. It is not unusual for a newly established ethics committee to meet monthly at first, then quarterly over the ensuing years, then semiannually, and then only on an as-needed basis. Securing physicians' commitment to take an active role in the ethics committee's work has proven very difficult. A recent study found that ethics committees average only three consults per year.[7]

Additionally, individuals (such as legal counsel or a risk manager) and other hospital committees (such as nursing quality assurance) who have been practicing clinical ethics (functionally, if not in name) long before an ethics committee was established in the hospital have not always welcomed an untested, unknown competitor with open arms. Indeed, they retain and often continue to exercise their power to short stop value-based conflicts before they ever reach the ethics committee.

Clinical Ethics and Ethics Consultation

When ethics committees were first getting established, each of the three practical applications of clinical ethics mentioned above (policy, education, and case consultation) was practiced by committee. However, because regular committee meetings rarely occur more often than once a month and because assembling the entire committee quickly, on an *ad hoc* basis, is difficult and deters the seeking of timely consultation, case consultation has increasingly devolved to clinical ethicists who serve on the committee's ethics consultation service.

Clinical ethic consultants are expected to timely respond to consultation requests. They commonly carry pagers and have on-call responsibilities. When consulted on a case these individuals typically:

- Discuss the patient's case with the attending physician, consulting physicians, nurses, the patient (if he or she is able), and family members;
- Review the patient's medical record;
- Organize patient care conferences; and
- Write entries in the progress notes documenting their ethical assessments and recommendations.

Members of the ethics consult service are drawn from a variety of professional backgrounds including medicine, surgery, nursing, social work, pastoral care, law, hospital administration, psychiatry, psychology, and academic philosophy. Thus the ethics consultant faces a challenge: to take advantage of his or her professional knowledge and training but avoid biasing the resolution of a value-based conflict by a procrustean reduction to a medical, surgical, spiritual, legal, psychiatric, or philosophical problem.

Medical/Surgical Consultation and Ethics Consultation

When physicians or surgeons initially apply for hospital privileges (and periodically thereafter), they must submit their credentials (medical degree, certification of residency, state medical license, fellowship, ABMS certification, work record of previous service) for review by medical staff, agree to a national practitioner database query, and undergo a criminal background check, all in support of a request for a delineation of privileges (DOP). The hospital credentials committee is responsible (and liable) for exercising due care in determining that every individual who operates under its authority in the hospital has sufficient knowledge, training, and skill to safely perform the services specified in his or her DOP. This due diligence is not equally applied to ethics committee members who perform consults in the hospital.

Despite the fact that the medical staff bylaws define the ethics committee's membership, functions, and services, the credentials committee typically does not evaluate the professional training and experience of individuals privileged to provide ethics consultation in the hospital. For example, suppose a medical doctor or surgeon member of the medical staff has been appointed to the ethics committee with a 0.5 FTE for service as an ethics consultant. Medical staff membership implies that he or she already has a DOP that may include, for example, colonoscopy, central venous catheter placement, hemodialysis, or placement of drug-eluting stents in the coronary arteries. Ethics consultation has been defined as "…the provision of *specialized help* in identifying, analyzing, and resolving ethical problems that arise in clinical care."[8] Assume that a hypothetical DOP for clinical ethics consultation would specify as privileges the activities mentioned above (to interview a patient's attending physician and nurses; to review all relevant aspects of a patient's chart, including other consultants' notes; and to write progress notes in the chart that include an ethical analysis of the value-based conflict presented by the case, together with recommendations for next steps or a reasonable resolution).

What education, training, and skill should be demanded in support of a DOP for reasonably resolving value-based conflicts and uncertainties in patient care? Having sufficient education, training, and skill to secure a DOP that includes colonoscopy would not necessarily be found sufficient for a DOP that includes laparoscopic hernia repair. Similarly, having sufficient education, training, and skill for either of those privileges would not necessarily support a DOP for ethics consultation. Comparatively few physicians have had a course in medical ethics. Fewer still have had any training in conflict resolution. Now, suppose the would-be ethics consultant is a cleric, nurse, social worker, lawyer, or philosopher. Wouldn't it seem reasonable that the credentials committee should evaluate his or her terminal degree, certifications, if any, graduate level course work in ethics, and references testifying to the applicant's probity, impartiality, and good judgment before approving a DOP for ethics consultation? This does not happen today.

Clinical Ethics and Patient Advocacy

Any person who is sick enough to warrant hospital admission is not at his best, not capable of jealously looking out for and defending the interests that his illness puts at risk. Well-known health care lawyer George Annas argues that every hospitalized patient needs a personal advocate.[9] The advocate Annas has in mind is a vigilant individual, ideally at the bedside 24-hours-a-day. He continuously monitors the patient's condition for any worrisome change and speaks up promptly, aggressively, and insistently to alert hospital staff. To prevent injury from errors, the advocates scrutinizes and records the name of every care provider and every intervention directed at the patient, challenging any that don't make sense.

Advocacy presupposes adversity.[10] If so, patient advocates must have adversaries. And in Annas's scheme of things, the hospital and all those who work in it should be regarded not simply as caregivers but also as potential patient adversaries. Their work burden, momentary attention lapses, and the general human tendency to rely on a routine instead of investigating every irregularity may all imperil the patient.

Annas summarily dismisses the suggestion that everyone in the hospital and especially its nurses and doctors are patient advocates. They are not, nor can they be. Their loyalties are divided among other patients; duties to partners, colleagues, and managed care plans; documentation duties; hospital politics; and other concerns. But if doctors and nurses cannot be patient advocates, neither can practitioners of clinical ethics — not in Annas's sense. Nor should they try.

Patients have rights. The clinical ethicist must see that these rights are known and respected — within a framework of customary understandings that includes due respect for provider responsibilities, including upholding applicable institutional rules. Patient rights have limits. Annas's patient advocate is not inherently concerned about those, nor is he necessarily reasonable in asserting the patient's rights. Instead, the advocate aggressively speaks up for and pushes the interests of the patient against all resistance posed by adversaries. Such vigorous advocacy poses a risk—needlessly proliferating adversaries. The ideal patient advocate relents only when further aggressive assertion risks making the patient worse off, at the limit when no one remains a willing provider of service.

Criticism of Clinical Ethics

Some critics doubt that there is such a thing as expertise in clinical ethics.[11] They wonder what teachable professional competence would underwrite a clinical skill in reasonably resolving value-based conflicts in patient care. What scholarly methodology would enable its experts reliably to generate solutions to such problems?

This challenge expresses a version of methodological skepticism. The argument is that claims of moral knowledge and ethical expertise necessarily presuppose a logically coherent methodology, mastery of which enables an expert to derive moral truths and univocal resolution of value-based conflicts and uncertainties. But, manifestly, no such method exists. Therefore the clinical ethicist's pretensions to have moral knowledge and/or ethical expertise are unfounded.

The major premise of this criticism is false. No discipline has such a methodology—not the natural sciences, not mathematics, and not the social sciences. More than 2,300 years ago, Aristotle warned that in ethics we must not demand greater precision and rigor than the subject matter admits. And indeed, in ethics we are stuck with vague concepts such as "appropriate/inappropriate," and conflicting principles such as patient autonomy/patient-centered-paternalism that fuel persistent disagreements about the scope of patient rights and the limits of fiduciary responsibility. Nevertheless we are able to separate ill-considered opinions from those that are well-grounded in those customary understandings that enable rational discussion of what should be done.

Critics of professionalizing clinical ethics point to an apparent irony—clinical ethics consultants lack a code of ethics with a provision declaring where their professional loyalty lies. Ethics consultants have a conflict of interest by virtue of being on the hospital's medical staff or being its employee. Or might not the ethics consult's commitment to certain religious beliefs (or his lack of commitment to any such beliefs) or his political or cultural beliefs color his judgment? If so, shouldn't the ethics consultant declare all known sources of bias that apply to him so that others may discount his bona fides at a rate that seems good to them? A code of ethics would make public what interests the ethics consultant serves and what interests should trump in conflicts. Finally, might not a hospital's having an ethics consultation service create a moral hazard by encouraging its clinicians to delegate their problems to the ethics consultant rather than shoulder the responsibility themselves? Each of these criticisms has merit, but of different kinds.

Hospitals and their medical staffs should ensure that individuals on the ethics consult service are competent and can be trusted with their privileges. Currently, there is no customary understanding regarding how this should be done. Is it alarming the clinical ethicists lack a code of ethics? That depends on whether one suspects that, but for a code of ethics, ethics consultants are at liberty to engage in rogue behavior, violate patients' rights, and put at risk the interests of everyone in the hospital. "Loose cannons" have a short shelf life, and appropriately so.

Recommendations from an ethics committee or consultant are simply that: recommendations. Their actionable merit, if any, will be a function of their reasonableness as perceived by professionals who have the responsibility of deciding whether to accept them when deciding what to do. Clinical ethics, as defined in this article, is a discipline of very long-standing, albeit informal as a practice. It pre-dates ethic committees and their consultation services. The fact that most ethics committees are rarely consulted, on average getting three consults per year,[7] suggests that most value-based conflicts in patient care are managed outside of the ethics committee or its consult service. Codes of ethics or certification for ethics consultants will not necessarily attract more business.

Conflicts of interest are problematic but also as numerous as the incentives presented by a particular situation; the motivational tendency of each is variable. Will an ethics consultant automatically bias his or her judgment toward the interests of whoever pays him? If so, does that mean paying attention to interests independent from those of effectively performing his assigned duties? Indeed, there is no reason to suppose that an ethics consultant would have any special insight into the larger interests of the medical staff, the nursing staff, or the hospital or that it would be somehow advantageous for him to pursue those interests rather than the tasks alluded to above.

I have argued that clinical ethics is a practical discipline. It is not new. Its practitioners, providers of ethics advice, have long been on service in the hospital. By contrast, having individuals in the hospital who self-identify as "clinical ethicists" is comparatively new. These newcomers have not yet achieved widespread success in wresting the practice from their much better established competitors. Nor will they succeed until and unless they are perceived by the community they seek to serve as providing a truly valuable service, at least marginally better than those they (unknowingly) compete with. **NCMJ**

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Promoting Informed Decision-Making in a Primary Care Practice by Implementing Decision Aids

Carmen L. Lewis, MD, MPH; Michael P. Pignone, MD, MPH

Empowering patients to be effective advocates for their health requires that they have adequate information and understanding about their health conditions. Many patients have limited health literacy which is a marker for vulnerability and a risk factor for poor health outcomes.[1] Providing vulnerable patients with information in a format they can easily access is challenging. One novel approach is to modify processes of clinical care so that medical practices deliver necessary and accessible information to patients in conjunction with their provider's visit. The goal is to improve the quality of medical care in clinical practice by promoting informed decision-making.[2]

Ethical principles support informed decision-making. Patients should be aware of the choices and treatments for their medical care, the potential outcomes of these choices and treatments, and have their personal values considered in decisions about their medical care. Although ethical principles support informed decision-making, evidence suggests that these ideals are not always being met in clinical practice. According to criteria developed by Braddock and colleagues, a minority of patient decisions are actually informed.[3] Using the least stringent criteria, they found that approximately 20% of interactions met the criteria for an informed decision. These studies, and others, indicate that improvements are needed to ensure that informed decision-making is occurring in clinical practice.[3-6]

> *"Patients should be aware of the choices and treatments for their medical care, the potential outcomes of these choices and treatments, and have their personal values considered in decisions about their medical care."*

Barriers to Informed Decision-Making

Multiple barriers at the provider, patient, and system levels impede informed decision-making. At the provider level, competing demands and limitations imposed by the current standard of time of clinical encounters are important barriers. In addition, providers are not typically trained to facilitate informed decision-making in clinical practice. Patients may have limited knowledge and/or low health literacy. Additionally, they may have little experience participating in medical or health decisions and may not recognize the important role they can play in clarifying their values and incorporating them into decisions. System barriers include low compensation for time spent in decision-making compared with compensation for performing procedures and inadequate infrastructure to support decision-making, such as reminder systems, registries, or scheduling systems.

Potential Approaches to Promote Informed Decision-Making

Several approaches could be employed to overcome barriers and to promote informed decision-making in clinical practice. One approach would be to target system barriers by increasing reimbursement that would allow for longer patient visits and providing resources for infrastructure that would facilitate informed decision-making. This approach involves policy

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changes on the national level. Another approach would be to train providers to implement informed decision-making. Studies to test whether this approach will be effective are being conducted.[7] However, systematic implementation of training is difficult and variation in physician uptake may decrease the net effectiveness of this approach. Another approach would be to educate patients about informed decision-making and thus modify expectations about interactions with their physicians. Again, adoption of this approach may vary and its effectiveness has not been established.

Practice-Based Approach to Promote Informed Decision-Making

Another approach would be to focus on helping individual practices implement decision support. Similar to the Chronic Care Model, practices could implement system changes that focus on decision support to bolster informed decision-making.[8] The rationale for this approach is that providing information to patients is the first critical step towards achieving informed decision-making. However, the consistency with which providers supply information for specific medical decisions is variable and may not be the most efficient use of their time. Relying on a systematic approach to provide information makes sense because it assures the fidelity and takes the burden of providing information away from the provider. The provider can then focus the time in the patient encounter on individualizing the decision-making process to the particular patient based on their personal values, which is the second critical step for informed decision-making.

Decision Aids to Promote Informed Decision-Making

Decision aids are promising tools that serve to provide information to patients and prepare them for their visit with the provider. Decision aids assist with identifying the nature of the decision, inform patients about the relevant options, present information regarding the consequences of the different options (benefits, harms, costs), help the patient assess his or her values with respect to the decision in question, and prepare the patient to use this information to reach a decision along with his or her provider. Decision aids have been developed in paper-based, video, and computer formats and have addressed a range of health questions from preventive services (e.g., prostate cancer screening) to single-event treatment decisions (e.g., breast conserving therapy vs. mastectomy for breast cancer) to treatment of chronic conditions (e.g., therapy for benign prostatic hyperplasia).[9] Decision aids delivered in a video format are particularly useful, as they may help patients overcome health literacy barriers.

One of the advantages of using patient decision aids is that robust evidence supports their effectiveness. Effectiveness of decision aids was demonstrated in a recent Cochrane Collaboration systematic review of 55 randomized trials.[9,10] Patients who view decision aids have increased knowledge and more realistic expectations about their treatment options. Decision aids also increased the likelihood that individuals prefer an active to a passive role in clinical decision-making.

Implementation of Decision Aids

Although decision aids have been shown in randomized trials to be effective in promoting informed decision-making, there is little data available on how best to implement them in clinical practice. In our internal medicine practice at the University of North Carolina (UNC), we have been testing ways to improve the quality of decision-making for our patients with a goal of achieving informed decision-making. In this commentary, we will share our experience and plans, as we believe that implementing decision aids has the potential to empower patients, overcome health literacy issues, and improve the quality of medical care.

Patient Decision Quality Initiative at UNC

The cornerstone of our initiative is the use of video decision aids, either in a DVD format or by streaming video over the internet. To promote decision aids, we have undertaken efforts to redesign our practice systems and develop a culture change focused on providing decision support to our patients.

Implementation of decision aids in primary care is known to be difficult. We have identified several key elements to the effective delivery of decision aids. Achieving high levels of decision aid use requires: (1) that the practice be able to identify which patients are eligible for specific decision aids and then communicate this information to the providers and/or the patient; (2) that the practice determine how best to deliver decision aids to the eligible patients, including determining when and where the decision aid should be viewed and who within the practice should be responsible for making sure the patient receives the decision aid; and (3) that the practice ensures that the patient is able to have any remaining questions answered after viewing.

Identifying Patients Eligible for Decision Aids

We are developing an automated process using administrative data (visit scheduling), clinical data from our electronic medical record (labs and tests), and financial billing data to identify potentially eligible patients for one or more decision aids. To augment this information we will also use patient-generated data from our computerized Health Risk Assessment for symptomatic conditions such as osteoarthritis or benign prostatic hyperplasia. We plan to use these automated systems to prioritize decision aid delivery based on a clinical algorithm and patient preferences and to provide delivery based on patient wishes, either electronically or by mail.

Decision Aid Delivery Systems

For the second step, the delivery of decision aids, we have tested the effectiveness and efficiency of several delivery models. With support from the nonprofit Foundation for Informed Medical Decision Making,[11] we tested several different delivery systems (see Table 1).

The mail-out approach reached the greatest number of our patients, but decision aid viewing was limited (8%).[12] When viewing was facilitated by a care assistant, decision aid viewing increased (66% viewed a portion of the decision aid), but knowledge about the material was adequate in only about one-quarter of the patients. When these two approaches were combined, almost three-fourths of the patients (71%)

Table 1.
Delivery Models for Decision Aids

Delivery Model	Rationale	Process	Topic	Efficacy
Mail-out[a]	Maximize number of patients getting decision aid	Mailed to patients due for screening.	CRC screening: *Colon Cancer Screening: Deciding What's Right for You*	Compared to usual care, 11% increase in CRC screening in attending physician patients with 8% of patients reporting viewing the decision aid; no increase in CRC screening in resident physician patients
In clinic by care assistant[b] who is charged with delivering decision aids to patients	Maximize viewing of decision aid	Care assistant facilitated in clinic, using a portable DVD player, administering a knowledge survey, entered the viewing status and knowledge score into the electronic medical record to alert the physician.	PSA screening: *Is Having a PSA Test Right for You?* Bariatric Weight Loss Surgery: *Weight Loss Surgery: Is it Right for You?*	66% viewed a portion of the decision aid and 27% answered three knowledge questions correctly
Prior to visit, mail-out with in-clinic follow up by care assistant	Decrease distractions of in-clinic viewing and maximize knowledge	Using the mail-out approach, prior to an upcoming visit with the care assistant following up during their visit to determine viewing status, administer knowledge questions, and encourage in-clinic viewing if they had not watched the video.	PSA screening: *Is Having a PSA Test Right for You?*	71% viewed a portion of the decision aid and 51% answered three knowledge questions correctly
Office staff delivery of decision aids using CQI techniques to implement changes in staff responsibilities	Care assistant too resource intensive; difficult to sustain	Re-design our practice practice work flow in order to prioritize decision aid delivery by front desk and nursing staff. To modify their responsibilities we will use CQI methodology, promoting change through a series of Plan-Do-Study-Act (PDSA) cycles.	8 to 10 decision aids	In progress

a Lewis CL, Brenner AT, Griffith JM, Pignone MP. The uptake and effect of a mailed multi-modal colon cancer screening intervention: a pilot controlled trial. *Implement Sci.* 2008;3:32.

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viewed a portion of the decision aid and about one-half had adequate knowledge after viewing. We conclude from this work that the combined approach will obtain the best reach, uptake, and fidelity.

Implementing multiple decision aids simultaneously may be too costly if we rely on care assistants to facilitate the process. We plan to redesign our practice work flow in order to prioritize decision aid delivery by front desk and nursing staff. To modify their responsibilities we will use Continuous Quality Improvement (CQI) methodology, promoting change through a series of Plan-Do-Study-Act (PDSA) cycles.[13]

Concerns in Vulnerable Populations

To date, use of decision aids has been tested primarily in more educated populations. This may be an important issue particularly for those with low educational attainment and limited health literacy who are at risk for poor health outcomes. Our initiative will provide patient decision aids in video format which may help overcome health literacy issues. On the other hand, a delivery system that only uses email or the internet could potentially exacerbate the "digital divide" among vulnerable patients with limited resources resulting in poorer health outcomes for these vulnerable patients.

Informed decision-making is an important component of quality medical care. To promote informed decision-making we have undertaken a new initiative to redesign our practice and develop a culture change focused on providing decision support to our patients. We believe that implementing decision aids has the potential to empower our patients, overcome low health literacy and other markers of vulnerability, and improve the quality of our medical care. **NCMJ**

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Disclosure and Apology:
Patient-Centered Approaches to the Public Health Problem of Medical Error

Catherine Cravens; Jo Anne L. Earp, ScD

The recognition of preventable medical errors as a public health problem of the size, magnitude, and cost equal to other chronic and acute illnesses or injuries long thought of as classic public health challenges occurred less than a decade ago. In 1999, the Institute of Medicine of the National Academies (IOM) released its groundbreaking report *To Err is Human: Building a Safer Health System*. Since that time we now know that as many as a million lives have been lost in US hospitals as a result of medical errors and that one-half of all surgical complications are preventable. The IOM estimated the cost of medical errors in hospitals alone as $17 to $29 billion a year. *To Err is Human* noted not only the high mortality and cost associated with medical errors, but went much further, reframing these errors as a chronic threat to public health, much like automobile accidents, breast cancer, and HIV/AIDS had been reframed in earlier IOM and other government reports.

Not surprisingly, such nascent recognition of a preventable population-level problem means that actual efforts to craft the complex interventions needed to mitigate the medical error problem are themselves no more than a few years old. Subsequent IOM[1] and other[2-4] reports went beyond simply defining and estimating the magnitude of the challenge, and suggested solutions that health care organizations might adopt to better ensure safety or even prevent medical error in the first place. These solutions included mandatory reporting systems,[4] tip lists,[5] and surgery checklists.[6] Despite these efforts, a groundswell endorsement of patient safety campaigns has not yet occurred.[2]

What is surprising, however, is how far physicians, other professionals, providers, and patient safety and quality care organizations have come in identifying targets for future research and intervention. Error disclosure is one topic that illustrates this trend at the system level through perceptions of risk, barriers to "apology laws;"[7] at the organizational level by functioning as a team, incorporating a culture of infallibility; and at the provider-patient level through challenges to transparency, strategies to achieve effective communication, and prompt disclosure. The next step is to begin to shift social norms to more widely embrace a belief in the effectiveness of disclosure accompanied by apology as a central tenet of any response. Taking such a next step, however, requires fuller empirical documentation, possibly randomized control trial data, if it is not to become simply a "bleeding heart" recommendation but a widely accepted imperative.

> ***"... increasing patient safety through improving patient-provider communication... means more frequent, more prompt disclosure of medical errors' occurrence and quicker, more earnest apologies once they have occurred."***

Our goal in this commentary is to define patient safety and the scope of medical errors, look briefly at root causes, and then identify disclosure and apology as a specific set of solutions for addressing medical errors in health care settings. Although a small but growing body of evidence exists on systematically addressing ways to ensure patient safety at regulatory, legislative, and organizational levels,[7] in this commentary we

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place special emphasis on increasing patient safety through improving patient-provider communication. In practice this means more frequent, more prompt disclosure of medical errors' occurrence and quicker, more earnest apologies once they have occurred.

Defining Medical Errors

What is a medical error? The IOM describes it as an act or omission that would have been judged wrong by knowledgeable peers at the time it occurred.[8] In defining patient safety, the Agency for Healthcare Research and Quality (AHRQ), the government entity primarily responsible for investigating the sources of medical errors, their scope, and strategies for reducing them—describes patient safety in a two-fold way as, "the absence of the potential for…healthcare-associated injury to patients created by avoiding medical errors" and "taking action to prevent errors from causing injury."[4] While somewhat convoluted as a definition, the important point about the AHRQ's statement is its inclusion of problems arising from actions not taken as well as from those mistakenly taken. Medical errors come in many forms and can result from an action that does not proceed as intended as often as an action taken incorrectly; there may be both errors of omission and commission.

The National Patient Safety Foundation further asserts that "errors may be made by any member of the health care team in any health care setting."[9] Similar to the etiology of other major public health problems, the sources of medical errors are numerous. They range from prescribing errors to poor surgical technique. Errors occur in diagnosis and missed diagnoses, in therapeutics and failed execution of intended treatment or even failure to treat in a timely manner, as well as "near misses."[10] Critical error incidents, defined by the American Society for Health Care Risk Management as "unexpected or unanticipated events or circumstances not consistent with the routine care of a particular patient, which could have, or did lead to, an unintended or unnecessary harm to a person, or a complaint, loss or damage,"[11] are so broadly defined as to make them a challenge to measure or as the subject of research. On the other hand, it is important to note that non-preventable adverse events, often referred to as medical complications, lie outside the AHRQ, IOM, and Risk Management Society's definitions, lacking, as they do, a component of provider awareness that a wrong has occurred. Although many, if not most, treatments are accompanied by the potential for complications, medical errors involve an element of *unnecessary* harm or *potentially avoidable* wrong judgment.

Although many medical errors are committed, almost always unintentionally, by individual health care providers every day, the root cause of most errors is not individual negligence. Rather, errors result from organizational-level deficiencies "caused by faulty systems, processes, and conditions that lead people to make mistakes or fail to prevent them."[8] While some level of error can be expected in any large scale organization, even individual medical errors usually stem from systematic factors such as over-reliance on human memory, unrealistic demands on human vigilance, or failure of communication.[10] Transitions from one venue or provider to another are frequently implicated in the occurrence of error.[12] Providers who lack appropriate knowledge, are fatigued, or are over-burdened are other common sources of adverse medical events.[13] Given the multiple systems that can go awry, it is not surprising that almost one-half the American public (42%)[14] has been touched by medical error, either personally or through friends and family. Indeed, more than one-third of all physicians have been involved in an error, half of these serious.[14]

Addressing Medical Errors

Given that errors are, and will undoubtedly remain, an inevitable part of medical care, how can we best address them? How can we also address those "near misses," the errors that patients never recognize that occur nevertheless? Although physicians are ethically required to report errors as a part of their commitment to act solely in the patient's interest, to tell the truth and to respect the patient as a person,[15,16] a grey area remains about whether reporting is obligatory only to existing state and federal agencies or to patients as well. As early as 1957 the American Medical Association (AMA) "enjoined" physicians to report errors, but their statement was ambiguous and ultimately left reporting to physicians' discretion.[15] The Ethics Manual of the American College of Physicians concurs with the AMA's sentiment, stating that disclosing errors to patients is respectful of patients and particularly respectful of patient autonomy.[15] The Patient Safety and Quality Improvement Act (PSQIA) of 2005 went several steps further and established a confidential—although voluntary—system for providers to report adverse medical events. Their intention was a dual one: to share data and to remove the fear of litigation.

While the PSQIA ruling does not mandate reporting of errors to patients themselves, but rather to patient safety organizations,[17,18] it nonetheless established a precedent for reporting adverse events that occur in a care setting. It is increasingly clear that reporting errors to state and federal agencies and/or professional organizations is a practice that not only should be encouraged, but one for which practitioners need legal protection. In 2006, then Senators Hillary Clinton and Barack Obama cosponsored federal legislation to make disclosure of mistakes, and apologies for them, inadmissible as evidence in court.[19] While reporting of errors directly to patients is not yet mandatory, the Joint Commission does require that *unanticipated outcomes* be disclosed to patients as part of the hospital accreditation process.[17] Hospitals found to be out of compliance, as discovered through a survey process or complaints filed with the Joint Commission, can jeopardize their accreditation status. However, the Joint Commission does not have the authority to impose sanctions such as fines, penalties, or closure, but instead leaves the imposition of such penalties up to federal, state, or local authorities.[20]

Professionals and health care organizations are often resistant to mandatory reporting of errors. As we discuss below, however, this practice can be beneficial for practitioners, organizations, and patients. Undoubtedly the perceived benefits of disclosure are the reason why a number of prestigious medical schools including Johns Hopkins, Harvard, Michigan, Stanford, and University of Illinois at Chicago and hospitals, including Kaiser and Minneapolis Children's, have made efforts to bring to light and document errors that have occurred in their hospitals. As Rowe states, "Hiding errors denies to the practice of medicine and, ultimately, to all patients, the opportunity to turn errors into learning that could prevent future errors."[15] While prevention of future errors and improvements in the quality of medical care are central to the reporting argument, the relatively new federal policy that forbids Medicare reimbursement for procedures necessitated by the need to repair medical problems resulting from error, bolsters this idea with sanctions.[21] The heart of the transparency campaign, however, for patient safety pioneers such as Donald Berwick and Atul Gawande is the delivery of patient-centered care, with its mandate to physicians to provide care that is respectful of and responsive to individual patient preferences, needs, and values, and that ensures patient values guide all clinical decisions.[22,23] The patient-physician relationship is also at stake; concealing errors significantly diminishes the trust that is central to that relationship. It remains a researchable question whether it also fuels lawsuits by indignant patients who discover the truth.[24]

Negative consequences of hiding adverse medical events occur at all levels. What is needed now is for health services researchers to design and test organizationally feasible, easily replicable, and reliably disseminated interventions to enhance transparency or enable greater disclosure. To get the most from future intervention trials, several earlier steps in patient advocacy research must happen. We need to examine systematically not only the circumstances under which errors are revealed versus concealed, but also to identify what the subjective versus objective barriers to full disclosure are, as well as those factors that make disclosure of adverse events to patients and their families easier.

Disclosure of Medical Errors

From the oft quoted admonition of Hippocrates, "First, do no harm," to the more prosaic "Honesty is the best policy," the reporting of medical errors could be viewed as a cultural expectation by our society. Recent studies of Judeo-Christian traditions of confession, repentance, and forgiveness underlying medical error disclosure also reflect these cultural expectations.[25] Furthermore, it is questionable whether patients can give true informed consent, required not only for informed medical decision-making, but also for subsequent medical treatment, if they are unaware of all that has transpired during their hospital or nursing home stay. Yet recent studies suggest that only one in four errors is disclosed.[26] Unfortunately, if physicians or other health care providers do not acknowledge medical errors, most such errors will remain undiscovered by patients.[27]

It is likely that reporting of medical errors to patients can be beneficial for physicians as well. This is a challenging area of research, obviously, given that before the benefits of acknowledging error can be documented physicians must first be trained to recognize errors that occur and then to overcome their strongly socialized reluctance to disclose them. Wu and colleagues suggest that because of their training, and particularly the implicit cultural expectations and social norms that constrain physicians' emotional repertoire, they often silently bear the burden of medical errors in an attempt to uphold expectations about the infallibility of doctors.[16] As one physician put it, "We have been trained to feel that if we were just alert enough, smart enough, and dedicated enough, we should have been able to overcome whatever impediments we encountered."[28]

To turn what is still most often viewed as a secret badge of shame worn by an individual into an institutional learning process will require hospital improvement committees to openly examine and discuss cases that, until now, have likely been handled in anything but a transparent manner.[24] Besides providing a teaching opportunity and reinforcing the trust that is at the heart of the doctor-patient relationship,[7] disclosing errors to patients can be a source of emotional relief, especially when forgiveness is offered by the patient or family. In fact, "full disclosure after a medical error reduces the likelihood that patients will change physicians, improves patient satisfaction, increases trust in the physician, and results in a more positive emotional response."[29] Further, some evidence suggests that disclosure of medical errors may reduce malpractice claims,[30,31] presumably by defusing the anger that often fuels lawsuits. A humanistic risk management policy[30] in which full disclosure, apology, and fair compensation is offered may also result in lower litigations costs arising from medical error.[7] After adopting a full disclosure policy, the University of Michigan reported a significant reduction in both malpractice claims and legal expenses, as did the VA Medical Center in Lexington, Kentucky.[7]

Perhaps the greatest barrier to full disclosure is the fear of legal repercussions, including medical malpractice suits. To date, however, we could find no evidence to suggest that full disclosure increases the risk of negative consequences for physicians.[29] Perhaps this is the case because the vast majority of patients who suffer from medical errors never file malpractice claims,[32] possibly because they are unaware those errors occurred. Thus, it remains a researchable question whether, if disclosure rates were higher, malpractice claims would rise.[33] It is evident that many lawyers believe they would, since they routinely counsel their physician clients against disclosure of such errors.[34,35] Yet some evidence suggests that the reverse is true, i.e., that when a patient suspects an error has occurred, nondisclosure actually increases the likelihood of patients seeking legal advice. There is evidence that many patients who do file suit do so in an attempt to understand what happened to them and to prevent future injury to others.[36] While disclosure may seem counterintuitive to reducing the number of medical malpractice suits filed, there are lessons to be learned from the experiences of the VA hospital in Lexington, Kentucky, mentioned above. This VA Medical Center settled more claims out of court, won more verdicts in court, and decreased the amount of money paid out per claim after embracing a full disclosure and fair settlement policy.[7] Their liability payments after adoption of the policy remained comparable to those of similar facilities.[30] As a result of the success of this policy at the Lexington VA, a full disclosure policy was adopted across all hospitals in the VA system.[37]

Disclosure can have important benefits for patients as well as providers. While physicians may be hesitant to report errors to patients, research suggests that patients want to be told about errors. A review of 17 studies revealed that "patients prefer detailed disclosure about what happened, why it happened, the consequences, and strategies for preventing future errors."[38] Furthermore, if mistakes are not acknowledged in a timely manner the appearance of a cover-up may lead to even more negative outcomes. In fact, failure to disclose an error to a patient can exacerbate families' suffering and intensify patients' anger.[39]

While there appear to be benefits of disclosure for both physicians and patients, several barriers other than medical culture norms affect physicians' decisions to fully disclose adverse medical events. First, some physicians believe that by not providing detailed information, they can protect their patients from undue anxiety.[40] Often they see no useful purpose being served by full disclosure while simply reducing patients' confidence in physicians and the medical system. In addition, physicians often feel that disclosure is time consuming, difficult to do, erodes patients' trust, and unfairly targets doctors as the sole source of what is often an institutional mistake.[40] For example, what appears to be a prescribing error may instead be a medication labeling or shelving problem.[8] While it is hard to make a case for disclosure not being time consuming, for the most part the other barriers have not been documented as occurring more frequently when medical error reporting increases.

In the case of those physicians who do want to fully disclose an error, most have little or no experience having this type of conversation with their patients. Because of a lack of training in medical error disclosure, many well-intended opportunities for these conversations may be missed.[41] What is needed is to include disclosure as a standard part of every medical student's training. We should be teaching physicians how to provide a detailed explanation in a truthful and compassionate manner, how to include a sincere apology following the disclosure, and also how to provide assurances that steps will be taken so that the error does not occur again, to them or to anyone else.[42] Pragmatically our emphasis on the importance of disclosure and methods for teaching physicians how to be forthright with patients and their families when errors occur, as well as our support for state "apology laws" to protect physicians who admit mistakes and try to make amends, might suggest that we believe our present health care system probably can't eliminate most risks, and hence errors. In addition, when faced with a public health problem of the magnitude of preventable medical errors, transparency about errors' occurrence and forthrightness about the impossibility of eliminating them completely would seem to be called for. Moreover, medical school mentors and role models could attempt to reframe providers' views of risk to teach trainees that "mistakes happen" and that, when they do, it is beneficial for them to occur in an institutional climate of transparency where "patient safety is not about blaming doctors but finding ways to build safety into the larger system."[43] A first step in initiating changes such as these is for practitioners and patients to join together often as equal members of patient and family hospital advisory boards to improve patterns of communication.[44] In this way, if there are error-prone physicians whose negligence should be spotlighted, a more transparent reporting environment is likely to highlight or underscore such cases.

Apologies for Medical Errors

While disclosure is the communication of the facts, regret or apology is an expression of remorse for those facts. These two actions do not always go hand in hand.[45] As stated earlier, we believe it is an ethical obligation for physicians to disclose errors to patients. The elements a disclosure should include, however, are often left to the discretion of the individual physician. While the Joint Commission and some states require disclosure, the evidence base for how such disclosure conversations should proceed is lacking. In 2004, the National Quality Forum recommended that physicians and other providers offer expressions of regret to patients at the time an error is disclosed.[36]

A lack of consensus among providers exists not only about whether to apologize following an error but also about *how* to apologize. This dissension makes it more likely that patients' expectations vis-à-vis disclosure (i.e., that they have a right to be told when an error occurs, receive an apology, and receive assurances that steps are being taken to prevent similar events in the future)[29] are not being met.[46] Resistance to and misconceptions about apologies is very similar to resistance and misconceptions about full disclosure. Perhaps the most notable source of physicians' hesitation is fear of litigation, as discussed earlier, even though most patients injured through medical negligence do *not* seek to take legal action.[45] Further, it seems equally possible that patients will sue less often if physicians apologize for errors and take responsibility for them.[36] It may even be the case that a failure to offer an apology leads more often to litigation, rather than the opposite.

Another common argument against the use of full disclosure and apology is the belief that it holds limited value. Yet the increasing number of medical institutions that have instituted disclosure and apology policies raises questions about the empirical validity of such a belief. Beyond the possible financial and institutional benefits, apologies hold perhaps their greatest appeal on a personal level. The use of apology is often part of the healing process for both the patient and the physician, and its therapeutic value should not be underestimated.[16,48] An apology may remove or reduce emotion so that the focus can shift from recrimination toward resolution. An apology can also restore power to the patient by demonstrating how changes will be made to prevent similar errors in the future.[49] Apologies also provide assurance of shared values between provider and patient, an essential element for continued trust.[49] By accepting responsibility and apologizing, the physician can begin restoring confidence to the patient that was probably shaken as a result of the error and/or any cover-up of it. As Lazare has put it, to move forward, "the patient must have confidence that the physician or facility is committed to correcting the faulty procedures and avoiding similar offenses."[49] In essence, apologies can reduce the toxicity of the environment and increase optimism that solutions are possible, or at least worth looking for. In this way institutional and personal energies can be directed toward finding future common ground rather than mired in dissecting past mistakes or repeating debilitating recriminations.

While an apology may seem instinctual, not all apologies meet the criteria for relieving the anxiety associated with medical errors. In fact, if done with insincerity, ambivalence, or disingenuousness, expressions of regret may exacerbate, rather than relieve, negative feelings or tensions.[49]

Table 1.
Guiding Principles to Effectively Implement Disclosure and Apology in Practice

The Five "R's" of Apology[48]	
Recognition	Understand the patient's feelings, your own feelings, and the basis for these feelings. Recognize when an apology is in order.
Regret	Respond to patients with empathy and acknowledge their feelings. Tell them you regret what they are going going through. Remember that an apology does not imply guilt.
Responsibility	Acknowledge responsibility for what happened and disclose all the details that led to the outcome.
Remedy	Make clear to the patient what is being done to remedy the problem. Discuss what costs or financial reparations they think would be appropriate.
Remain Engaged	Focus on providing continuous care for your patient after the outcome. By remaining engaged, you reassure patients that you will be there for them.
The Five "A's" of Making Amends[31]	
Accurate	Truthfully and accurately report to the patient that an error occurred.
Answers	Anticipate a patient's need for answers about what the error was and what its clinical implications are.
Accountability	Explain how the error occurred. Be accountable to the patient and family about future actions to prevent similar errors from occurring.
Apology	Apologize to the patient for the error.
Acknowledge	Acknowledge the patient's range of emotions caused by the error and address any concerns raised.

Delivering an Apology

Effective disclosure and apologies have several different elements (see Table 1). These elements should be implemented only after it has been definitively determined that an error has occurred. If an investigation is ongoing, keeping patients and their families informed of its progress, and eventually its findings, is a must. When apologizing, do the following:

1) **Express empathy.**
   Empathy should always be expressed, even before the root cause of the error has been discovered, in an effort to mitigate any anger that may exist toward the physician and restore trust in the patient-physician relationship. Expressing empathy is not the same as admitting fault.

   Do say: "I am sorry we did this to you." Follow up with "I want to help you understand what happened and what we are doing to support you and make sure such a mistake won't happen (to others) again."

   Do *not* say: "Mistakes happen" or, even, "I am sorry this happened to you."

2) **Admit fault.**
   Once it has been documented that an error has occurred, the next step is to take ownership of the error and continue with a full apology to the patient and/or family members for its occurrence.

3) **Explain what happened.**
   Disclose all the details that led to the error and explain why it happened. Language should be appropriate for the patient, and tone and format should be conversational. This step should include, if possible, letting patients know how such errors will be prevented in the future.

4) **Offer compensation and/or fix the problem.**
While most compensation will be monetary, including the costs of fixing the error, several other forms of compensation are possible. Examples include paid lodging and meals (for family members as well as patients) while the problem is being resolved; an endowment set up in the patient's or loved one's name; lost wages for the period of recovery; or naming a lecture series on errors, patient safety, and disclosure in honor of a patient who has passed away because of an error.[50]

Before beginning a disclosure and apology conversation, providers need to pick a time and place that is comfortable for the patient. In many cases, this time may not be immediately after the error occurred. In order to deliver an effective apology that is well-received, providers must take time to reflect before speaking with patients erred against. This is a time in which physicians can attempt to come to terms with what has happened, try to understand the problem from the patient's perspective, and start to forgive themselves for their role in the incident.[48]

When the conversation begins, the physician should sit down with the family so that all parties are eye to eye. He or she should speak slowly and pause often to solicit and answer questions. This dialogue should be a conversation rather than a lecture or a series of rationalizations, two-sided rather than one-sided. Most importantly, physicians need to be honest and sincere. For the most part, patients are interested in learning what happened, not in gaining some sort of confession to be used against the physician later on.[32,36] While apologizing may seem like a logical and simple, if uncomfortable, process, it can often be very complicated and anxiety-provoking for those inexperienced with saying "I'm sorry." Practicing these conversations first can help ensure that they proceed as intended.

Implementing Disclosure and Apology Policies

Although many barriers still exist to fully implementing a disclosure and apology policy when a medical error occurs, most of the barriers stem from strongly held, but empirically unsupported, beliefs that are reinforced by the gestalt of medical culture and perhaps a historical lag in the normative expectations about what it means to be a physician. Training programs can change these beliefs and norms. Legislation such as apology laws can make these changes easier to bring about. Economic sanctions may hasten the change. As of yet, however, neither providers nor the public have fully acknowledged that medical errors are a public health problem and, like other public health problems, its etiology, size, and methods for prevention or amelioration are describable, systemic, and treatable. Until this level of recognition is achieved, medical educators and legislative champions of transparency will have a difficult time instituting programs to reduce the problem or mitigate its results. Inevitably, however, as awareness and acceptance of the magnitude, causes, and impact of errors grow, and their systematic, although often hidden, nature is exposed, disclosure of errors and apologies for them will occur more frequently, as a result of training programs to prevent as well as reframe and defuse them. The trajectory this process takes will in some ways parallel the trajectory for achieving true patient-centered care. Patient advocacy efforts and commentaries, such as those included in this issue of the *Journal*, will be important in the effort to bring about greater health care quality, more transparent interactions between providers and patients, and ultimately achieve the IOM's vision for patient-centered care as the actual cornerstone of every medical encounter. **NCMJ**

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The Whole Story:
Narrative as a Clinical Tool

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Even the most comprehensive medical history cannot tell the whole story. Inevitably we have a main character—the patient. We also have a narrator—the provider. Descriptive details are relayed, although often in a rather cryptic narrative style. The tension derives from some aspect of ill health that has become sufficiently disabling so as to require medical attention. Information gained from the vital signs, lab tests, and physical examination may help to zero in on the immediate cause of the problem. A social history may reveal intriguing information about significant relationships and lifestyle factors that could be important both in understanding how the patient became ill in the first place and about mechanisms that may play a role in the healing process. Consider the following:

> Mr. Ford, a 61 year old white male, complains of persistent cough and shortness of breath. No evidence of acute infection. Past medical history includes poorly controlled hypertension, gastoesophageal reflux disease. Blood pressure today 150/90. Previous alcoholism, has been sober for 7 years. Smokes 1.5 packs per day since age 20. Advised smoking cessation using nicotine patch.

There is something missing. If Dr. Rachel Remen is correct that "Stories are someone's experience of the events in their life, they are not the events themselves,"[1] then the above paragraph is more data than narrative. We know something about the physical condition of Mr. Ford's body, and we can infer much about his lifestyle. Few would dispute his physician's interpretation of the data. Chronic smokers often experience the kind of symptoms described above. But we know nothing about Mr. Ford's experience, his story. We do not know whether he attributes his cough and shortness of breath to smoking. Has he tried to quit in the past? Does he want to quit now? In behavioral medicine, what Mr. Ford wants matters; his beliefs and desires are as important in determining his final health outcomes as any amount of medical data.

> ***"Without story, something about what makes the medical encounter uniquely human is missing. Recognizing the life story behind every medical history is a moral obligation that also has tremendous practical value."***

Many professions require the ability to fix something when it breaks. When my water pipes rupture, I call a plumber. When my computer catches a virus, I call an IT specialist. If I start having migraines, I call my doctor. What sets medicine apart from these other professions in the repair business? Only patients can tell stories. The water pipe cannot describe the constant wear and tear, the increasing pressure, the erosion that eventually culminates in a small explosion. The computer cannot recall possible sources of exposure nor describe the course of the illness. While the water pipe and the computer are entirely incapable of contributing to their own healing, most patients present with some ability to tell the story of their sickness.

I would argue that this unique capacity for patients to share the way in which they experience illness is a defining characteristic in the practice of medicine. Consider the opposite—practicing medicine in the absence of story. Ann Fadiman, in her book *The Spirit Catches You and You Fall Down*,[2] writes about the challenges associated with providing medical care for Hmong refugees in Merced, California in the 1980s. Both patients and providers experienced frustration when language barriers and cultural differences made it almost

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impossible to communicate story and interpretation. When asked about his strategy for treating Hmong patients who did not speak English, one physician likened his approach to practicing veterinary medicine. This comparison is both provocative and compelling. Without story, something about what makes the medical encounter uniquely human is missing.

Recognizing the life story behind every medical history is a moral obligation that also has tremendous practical value. The human potential to participate in the process of care suggests that patients can act in ways that facilitate or hinder certain health outcomes. In this era of chronic disease, primary care physicians spend untold hours making recommendations for behavior change that often seem to fall on deaf ears. The physician's assessment of a health problem and recommendation for appropriate treatment may be absolutely correct and in accord with clinical practice guidelines. But in medicine, technical accuracy does not guarantee a good outcome. If the patient does not agree with the physician's interpretation of the condition, it is unlikely that he or she will comply with recommended treatment. We can diagnose Mr. Ford's nicotine dependence based upon his medical history, but we cannot help him quit without knowing his story.

Patient stories often challenge our assumptions about the causes of suffering and the best ways to alleviate it. This is especially true when working in a cross-cultural context. In her book, Fadiman describes the attempts made by American clinicians to provide high quality Western medical treatment for epilepsy to the child of a Hmong family who believed their daughter Lia suffered from a spirit that caught her and made her fall down. The fundamental tension lay in the fact that the doctors wanted to treat Lia physically for what the Lee family viewed primarily as a spiritual concern. The stakes were as high as the chasm was wide. In the end, the best attempts to treat Lia medically left her in a persistent vegetative state and both her providers and her family grief-stricken and demoralized. Might a little more story have helped to bridge the gap?

We cannot expect to reach different places via the same path, so we might as well reconnoiter at the outset. The patient story informs the route and determines the final destination; it orients us to potential roadblocks and suggests maneuvers to overcome them. If we think that medical care can succeed apart from a shared understanding of the problem and the solution, we are fooling ourselves. Understanding the patient's perspective does not guarantee agreement between patient and physician about what is wrong or what to do about it. But at least it opens the door for real dialogue, ultimately making healing and wholeness possible. **NCMJ**

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Cross-Cultural Issues and Health Care Advocacy for Immigrants in North Carolina

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For those of us living in North Carolina, it is no surprise that in the past 20 years the face of our state has rapidly changed, with recent immigrants making up a growing number of those living and working in our state. The number of immigrants moving and relocating to North Carolina has increased in the past decades with the largest influx of immigrants coming from Latin America, mostly from Mexico. From 1990 to 2004, Latino immigrants accounted for about 27.5% of the population growth in the state, representing about 7% of the population in 2004, up from less than 1% in 1990.[1]

Moving to a new country is not an easy transition for most immigrants. Many long for years for their extended families, support networks, and country of birth but choose to remain in the United States in order to provide a better life for their children. Faced with learning another language and adapting to a different culture, immigrants struggle to understand and interpret a new set of beliefs regarding health and a new health care system. Since 9/11, the United States' approach to homeland security has been one of enforcing security on the border with Mexico, limiting valid immigrant visas to the United States, and deporting those immigrants who have committed certain types of crimes. Several of these policies have served to further marginalize immigrant communities living in our state and have ended up deterring many individuals from accessing the few health and human services still granted to them.

This commentary will do the following: (1) explore barriers that limit immigrants' access to health care; (2) focus on policies that lessen immigrants' sense of security and safety, negatively impacting their access to health care services and ultimately their health status; and (3) provide a set of recommendations for improving immigrants' access to health care in North Carolina.

Barriers That Limit Immigrants' Access to Health Care in North Carolina

The United States is facing a health care crisis, and many people living in the country, whether citizens or residents of the state, are struggling to access health care services. Barriers that further limit immigrants' access to preventive and medical care include the following:

> ***"Faced with learning another language and adapting to a different culture, immigrants struggle to understand and interpret a new set of beliefs regarding health and a new health care system."***

Lack of health insurance

Many immigrants to North Carolina traditionally work for smaller employers who do not provide health insurance, and they themselves cannot afford to pay the premiums to cover themselves and their families. Over one-half of the Latinos living in North Carolina are uninsured compared to about 20% of African Americans and 13% of whites. Furthermore, Latinos have higher percentages than whites and African Americans on measures of poor health care access including no current health insurance; could not see a doctor due to cost; and had no personal physician.[2,3]

Lack of bilingual and bicultural staff

Even though some health and human service agencies in North Carolina have hired bilingual and bicultural staff to address the needs of recent immigrants, the percentage of Latinos working in these organizations is still minimal. In 2006, the number of Latinos, as a proportion of those employed by the North Carolina Department of Health and

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Human Services, was less than 1%.[a] Having left family and friends behind, recent immigrants struggle to adapt to a new environment and to a new way of life, leaving them limited time to learn about the health system in their new home. This is complicated by North Carolina's health and human services infrastructure which is still in the process of developing effective ways to serve communities of people who are learning a new language, culture, and health care system.

Lack of trained and certified interpreters

Since numerous health and human service agencies throughout North Carolina do not yet have qualified bilingual and bicultural staff providing services, many have to rely on interpreters to serve individuals with limited English proficiency. North Carolina does not currently have state certification for medical interpreters; consequently, it is still common for interpreters working throughout health departments in the state to have received little or no formal training on medical vocabulary, interpreting techniques, or ethical and confidentiality standards. Without adequate bilingual and bicultural staff, and with no certification requirements for medical interpreters, immigrants with limited English proficiency are at a major disadvantage and consequently often receive less than adequate care.

Traumatic experiences in home country or when crossing a border (whether in the US, Mexico, or Central America)

Immigrants moving to North Carolina migrate for a variety of reasons, including escaping natural disasters, extreme poverty, war, and violence. Immigrants moving to North Carolina directly from Latin America often walk for days with little food or water to make it to the United States. It is common for many to experience traumatic events along the way while heading north and, once in their new country, to feel lonely and alienated from the majority society, lacking, as they usually do, any support system. As a result of these and other issues, depression, anxiety, and post-traumatic stress disorder (PTSD) are a few of the mental health issues faced by those who migrate to North Carolina.[4]

Traditional healing

A number of immigrant communities rely on traditional healing techniques or use herbs and other non-western healing tools frowned upon by some medical providers, often increasing immigrants' sense of alienation and rejection when coming in contact with health care providers.

Suspicion of or little trust in government

Having moved to North Carolina from countries where they experienced government corruption and human rights violations, many immigrants remain cautious about relying and accessing government support, including health departments and departments of social services. Furthermore, restrictive anti-immigrant policies instituted throughout the state and the nation increase fear of government and diminish trust in the system decreasing the likelihood that recent immigrants will consider and even feel safe accessing services.

Tensions That Have Led to Anti-Immigrant Measures and Policies

The following scenario summarizes an actual situation faced by a Latina working in Alamance County, a story that negatively impacts and will continue to impact Latino immigrants' sense of trust in the health care system and thus their access to adequate health care in our state:

> *You are an immigrant who moved to North Carolina when you were a little girl. Your parents brought you to this state in search of a better life for your family. You have been in this state so long that North Carolina is the only home you've ever known. You work at the local public library and are well-known and respected in the community. One day, you are arrested. You are placed in deportation proceedings. You are told that you were arrested because you were using someone else's social security number to work. You then learn that the local health department where you receive prenatal care has released your medical files to the Immigration and Customs Enforcement Agency (ICE), breaching the confidentiality you had been assured existed when you began receiving medical services there. Now your immigrant neighbors and friends are terrified to interact with government officials and are very apprehensive of seeking medical care services at the health department or elsewhere in the state.*

This incident provides a glimpse into the lives of many of the recent immigrants that have migrated to North Carolina and describes a few of the anti-immigrant attitudes and policies adopted by some government entities in our state. This incident received extensive media attention and was widely publicized in English- and Spanish-language media, which heightened immigrants' fears about accessing health care services, especially those offered by government agencies, and further eroded immigrants' trust in government entities and officials.

The following policies, adopted by our state in the past two years, divide families, foster anxiety and depression in children and adults, and decrease the likelihood that immigrants, because of fear of deportation, will seek preventive medical services for themselves and for their children.

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[a] M. Miranda, MPHE, public health consultant/training coordinator, NC Office of Minority Health and Health Disparities. Written communication. January 30, 2009.

Requiring social security numbers or valid visas to obtain a driver license

The North Carolina General Assembly passed a law effective in early 2007 that barred immigrants from using an Individual Taxpayer Identification Number (ITIN) or their *matrícula consular* as identifying documents for obtaining a driver license. The ITIN is a nine-digit number issued by the Internal Revenue Service for those individuals who do not have a social security number but who are working in the United States.[5] For many years, immigrant workers have used their ITIN to file their federal and state taxes and, until 2007, used it in place of a social security card as documentation when obtaining a driver license. The *matrícula consular* is an official document issued by the Mexican Consulate in Raleigh; until recently it could be used by Mexicans residing in North Carolina to verify their identity. Since 2007, thousands of immigrants in our state have been unable to renew or obtain their driver licenses. This law has left many immigrants with no reliable means of transportation, reducing the likelihood that they will risk driving without a license to access preventive care and increasing the chances that, in order to get emergency help, they will have to drive to the emergency room without a license.

287(g) Program

Section 287(g) of the Immigration and Nationality Act (INA) was initially developed as a federal program under an umbrella known as ICE ACCESS within the Department of Homeland Security. The 287(g) program seeks to fund local law enforcement to identify and apprehend "high risk criminal aliens." In reality, however, the 287(g) program has been implemented as a means of deporting otherwise law-abiding Latino residents for misdemeanor infractions, most of them being minor traffic violations. Eight North Carolina law enforcement agencies—the most of any state—now have officers trained by ICE including the sheriff's offices in Alamance, Cabarrus, Cumberland, Gaston, Henderson, Mecklenburg, and Wake counties, as well as in the Durham Police Department.[6] Between Secure Communities, another ICE ACCESS program, and 287(g), North Carolina is second in the nation (after Texas, which is a border state) in the number of programs instituted to remove undocumented immigrants from the country.[7] The 287(g) program perpetuates a climate of fear, decreases trust in law enforcement agency representatives, and results in the forced separation of families with negative consequences for their children, including "economic hardship, fear, isolation, social stigma, and psychological trauma."[8] This program, and other anti-immigrant initiatives, weaken families, separate members of our communities, and reduce immigrants' access to health care. In addition, these initiatives often create a state of panic, terrifying immigrants to "stay under the radar" and away from any services meant to enhance their health or support their adaptation into the community.

A number of Latino grassroots leaders, advocacy groups, and community-based organizations are working to improve living conditions for these communities, with the important goal of increasing access to health care through advocacy efforts at the state level. Several of these groups are working to support the following policy recommendations as methods to improve Latino immigrants' health status, and, in the process, improve the health of all residents in our state.

Recommendations for Immigrant-Related Policies

1. Adopt legislation to allow all North Carolina residents to obtain driver licenses. Return to the previous policy wherein North Carolina accepted ITINs and the *matrícula consular* as identifying documents. Adoption of this policy would produce safer roads and ensure greater accountability and public protection for crashes that occur. It would also provide additional revenue to our state from immigrants' purchasing cars, license plates, and car insurance policies.
2. Adopt legislation to stop deporting immigrant parents and separating them from their children. Eliminate the ICE ACCESS program, subsequently doing away with the 287(g) and the Secure Communities programs, or ensure that these programs are aimed only at those who have been convicted of serious crimes and not at those committing minor traffic violations. Reports to ICE from these law enforcement offices with ICE ACCESS programs indicate that upwards of 60% of those deported from Alamance, Cabarrus, Gaston, and Mecklenburg counties have allegedly committed misdemeanor infractions—most of these being traffic offenses.[9]
3. Adopt legislation that allows all students who graduate from North Carolina high schools to access community colleges and universities and pay in-state tuition. Having been brought to North Carolina as small children, many of these students, for all practical purposes, are North Carolinians, who if given the chance, could be productive and contributing members of our society. Denying these students equal opportunities will result in a permanent underclass with limited opportunities, increasing the likelihood that these youth will drop out of school, join gangs, and engage in risky behaviors which, among other things, could lead to sexually-transmitted infections and unplanned pregnancies.[10]

Title VI and HIPAA

4. Raise Latino immigrants' awareness of their rights and responsibilities under Title VI with respect to accessing services, protecting confidentiality, and where to go to report poor service delivery. Employ linguistically and culturally-appropriate media campaigns to raise health and human services agencies' awareness of Title VI and how to comply with this act. Enforce penalties for agencies not in compliance.

5. Ensure confidentiality of all information shared at every health and human services visit. Train all staff in health and human service agencies on HIPAA requirements and how to obey these requirements. Develop a linguistically and culturally appropriate media campaign about all health and human services organizations' commitment to confidentiality. Include in the campaign information on where individuals can call or write to make anonymous complaints about breaches of confidentiality.
6. Develop a state certification for medical interpreters to ensure that at least some interpreters in every health and human service organization are bilingual, bicultural, have medical knowledge and vocabulary in both English and Spanish, and have been trained on the ethical and confidential standards of interpreting.

Additional Recommendations

7. Adopt legislation to ensure that all North Carolina children have access to publicly-funded health insurance programs, regardless of their immigration status.
8. Support better living and working conditions for farmworkers. According to a 2007 publication of the North Carolina Farmworker Institute, close to 95% of migrant farmworkers in our state are Spanish-speakers. Most have no health insurance and many experience high-risk working and living conditions.[11]
9. Support the development of lay health advisor, or *promotores*, programs throughout North Carolina to help dispel myths and rumors about access to health care services and reduce the Latino community's fear of using such services. *Promotores* programs link community members to existing health and human services resources[12] and promote the adoption of measures to prevent disease and improve the public's health.

Immigration to this country, history reminds us, has been a constant for centuries, with immigrants being a major component of the fabric of our communities. The challenges for those moving to the United States continue to be numerous. Moreover, once in their new country, many immigrants are faced with an environment full of duality, where their labor is embraced but they, the laborers, their families, and their needs, are often rejected. At the height of the immigration debate, North Carolina is at a decisive moment in history and its people must decide whether to: (1) focus on enforcing immigration laws, on the institutionalization of racial profiling, and on the perpetuation of discriminatory policies which divide families and promote the dehumanization of an entire group living and working within our communities; or (2) help shape innovative policies that embrace and recognize the richness that immigrants bring to our communities and commit to investing in all of those living and working in our state. Given the new national focus on change, I urge North Carolinians to adopt policies that promote the health of its people and benefit all of those living in our state. **NCMJ**

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Advocacy for Refugees

Chloe Katz

Refugees are a population distinct from other immigrants in that they have been forced to leave their homes and relocate in other countries out of fear of persecution based on race, religion, ethnicity, political opinion, or social group.[1] The United States admits more refugees for permanent resettlement than any other nation[2] and data from the North Carolina Refugee Health Program at the Department of Health and Human Services[a] indicate that refugees are increasingly being resettled in North Carolina. In order to appropriately address the acute and long-term health issues of refugees arriving in North Carolina, physicians will be required to augment their current understanding of cultural competency to include topics of conflict-related violence and psychological evaluation.[1]

Studies report that refugees experience higher risk of psychiatric conditions, including depression, suicide, post-traumatic stress disorder (PTSD), and substance abuse, all of which are directly related to their past trauma.[3] Given that 5-10% of refugees who have come forward with their stories have experienced physical and psychological abuse, the need for mental health evaluation and treatment is crucial to healing.[3-5] This information is particularly salient to discussions of societal well-being, as children exposed to torture are vulnerable to destructive habits and abuse as adults,[6,7] as well as to neuropsychiatric disorders caused by brain injury and malnutrition.[8]

The current cultural competency curricula being used in many medical schools do not sufficiently train doctors to meet the health needs of their refugee patients.[9] Gavagan and colleagues recommend coverage of the following four points in a clinical evaluation, depending on the refugee's area of origin: (1) nutritional status, including children's growth and development; (2) mental health, focusing on PTSD, anxiety, physical abuse, and substance abuse; (3) infectious diseases; and (4) preventive screening.[10]

The strategies for implementing more comprehensive and culturally competent care require changes at the national policy level as well as the organizational and individual levels. On the policy level, an augmented curriculum that stresses recognition of refugees' unique needs should be universally disseminated, implemented, and tested.[11] There are institutions, such as Harvard and the University of Washington,[3] that advocate for the use of a more thorough evaluation of medical history and psychological state, one that inquires about the person's life story, medical history, path to host country, infectious diseases, traditional medicine, substance use, sexual history, and trauma history. This comprehensive evaluation, in addition to Harvard's Trauma Questionnaire, gives the provider a more thorough picture of the influences of violence and trauma on the patient's current and future health.[12]

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On the organizational level, health care settings should facilitate multidisciplinary teams that include health care providers, social workers, lawyers, and interpreters for refugee patients.[5] Lay health advisors and other community members can also help to bridge cultural barriers between providers and refugee patients. Furthermore, an interpreter familiar with the patient's culture can help with appropriate

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[a] J. Morillo, North Carolina refugee health coordinator, North Carolina Department of Health and Human Services. Personal communication, November 26, 2008.

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assessments,[3] dispelling negative myths about treatment and overcoming attitudinal barriers.[13]

Finally, providers must become more familiar with the populations they are serving. They should exhibit background knowledge and a genuine interest in the patient's culture and experience.[5,11,14] Health professionals should also keep in mind that the visit in which the evaluation is performed may be the patient's first physical or mental assessment of any kind. Extra sensitivity and caution is warranted, as well as mindfulness of the possibility that previous encounters with health professionals may have been in contexts of torture.[8] Several visits may be necessary before a trusting relationship can be established.[8]

In an age where international conflict is increasing, providers in states that host growing numbers of refugee populations should strategize ways to bring refugee populations in for care, ensure that refugees' perspectives are represented when redesigning and disseminating a more comprehensive curriculum, use interpreters in patient treatment, involve lay community members for refugee outreach, and couple with policymakers to garner the political and financial support to make these changes happen. These challenges will require not only an ethical commitment from health care providers but also a financial investment. As it stands, physicians often cite barriers such as a lack of time to be able to fully assess their patients and the hardships of caring for under- or uninsured patients.

Over the years several strategies have been developed to address the need for specific attention on refugee populations. There are programs in medical schools such as at State University of New York at Buffalo, for example, that allow students to gain cultural competency first-hand by working directly with refugee populations.[15] A formal program may not be necessary for health professionals to gain an insider perspective. The increase in refugee and immigrant populations provides a greater possibility for collaboration and sharing of intercultural perspectives. Providers may choose to gather with other health professionals to discuss the impact of globalization on their practices, to travel, or to seek background information relative to the patient's experience before the visit. **NCMJ**

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Improving Access and Quality of Care for African Americans with Advanced Cancer

Laura C. Hanson, MD, MPH

Advanced cancer may respond to treatment, but it is rarely curable. Most patients with advanced cancer have acquired the disease that will ultimately cause their death. Patients living with advanced cancer, and their families, need information and health services to alleviate the physical, emotional, and spiritual suffering caused by this diagnosis.

Scientific advances in palliative chemotherapy and radiation permit many patients to receive treatment to slow cancer growth and reduce symptoms. When advanced cancer is first diagnosed, pain management and supportive services may enable patients to feel well enough to receive these cancer therapies. When the harms and burdens of cancer treatments begin to outweigh potential benefits, patients with advanced cancer may still benefit from palliative care and hospice providers who provide expert management of pain and other symptoms and address emotional, spiritual, and practical needs.

Disparities in cancer care access and quality affect African Americans across all stages of cancer, from screening through treatment of early and advanced disease. Compared to whites, they experience lower rates of preventive screening, are more likely to be diagnosed with advanced stage disease, and receive less optimal treatment at all disease stages. This commentary will review potential strategies to improve access and quality of care for African Americans with advanced cancer, with an emphasis on the role of community-based health advocacy. Educational interventions to illuminate bias and enhance cultural competency are being tested for impact on health care providers' practices. However, health care provider training may be necessary but not sufficient to overcome health disparities. African American cultural values emphasize self-reliance and connection to family, community, and church as essential sources of support during times of struggle. Facing serious illness, African Americans may seek community-based sources of health information or advice. This essay will examine early evidence that health disparities can be reduced through provider-community partnerships to improve cancer care.

Health Disparities in Cancer Care

Health disparities for racial and ethnic minorities are a growing source of concern for providers, patients, and policymakers in North Carolina and the United States.[1-3] Among US ethnic groups, African Americans face well-documented disadvantages in their access to and quality of health care for many diseases, including life-threatening diseases such as cancer.[4] The African American experience differs across the continuum of cancer, with lower rates of screening and less optimal treatment for early and late stage disease.[5] African Americans are more likely to present with late stage or incurable cancer due to both delays in screening and biologic factors.[6] As a result, African Americans are at increased risk of dying from cancer.[7-15]

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African Americans have a higher incidence of colorectal, lung, and prostate cancer.[16] In North Carolina, as in the entire US, African American death rates are significantly higher for breast, prostate, and colorectal cancer (see Table 1).[17]

Health Disparities in Treatment for Pain

All patients with advanced cancer should expect excellent assessment and effective treatment for pain. However

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Table 1.
Age-Adjusted Death Rates per 100,000 People in North Carolina (2000-2004)

	White	African American
Breast cancer	23.5	33.3
Prostate cancer	25.1	73.0
Lung cancer	60.3	59.8
Colorectal cancer	18.0	25.4

patients from minority racial or ethnic groups, compared to the majority white population, have greater cancer pain severity and less effective treatment for pain. The Eastern Cooperative Oncology Group Minority Outpatient Pain Study studied cancer pain practices. Among 1,589 patients with pain, 65% of Latino and nonwhite patients with pain received inadequate analgesic prescriptions compared to 50% of white patients.[18,19] Physicians underestimated pain severity for 64% of Latino and 74% of African American patients.[20] Furthermore, nursing home residents with advanced cancer receive less adequate pain treatment if they are African American.[21,22] A longitudinal study of advanced cancer patients found reduced pain severity and disparities over time for patients who had similar access to treatment.[16]

Treatment Decisions, Communication, and Hospice Care

African Americans are more than twice as likely as whites to make choices in favor of life-prolonging treatment.[23] As a result, they are less likely to access hospice care and other supportive services when all cancer treatment options are exhausted—22% of African Americans compared to 29% of whites used hospice care during their final illness.[24] African Americans are less likely than whites to have written advance directives.[25-30] They are also more likely to die receiving life-sustaining rather than palliative treatments.[31,32] If these choices are fully informed, they are ethically appropriate. However, African American patients are also less likely to communicate about treatment choices with their physicians.[33-35] As a result, some patients and families may not access pain management, palliative care, or hospice due to lack of informed decision-making.

Causes of Health Disparities

Health disparities have multiple causes. Breast and prostate cancer have demonstrable biologic differences in African Americans, triggering earlier and more aggressive disease onset.[36] However, biologic factors alone do not explain differential mortality, since African American and white women who receive similar access to breast cancer treatment have comparable survival rates.[37] Non-biologic determinants include: (1) socioeconomic factors such as poverty and lack of health education; (2) social injustice including intentional and unintentional discrimination by health care providers; and (3) cultural influences affecting health beliefs, health behaviors, and the shared understanding necessary for communication between patients and health care providers.

Trust is the core attribute of the fiduciary relationship between doctor and patient. Distrust will impede discussions of subjective and value-laden experiences, such as pain, suffering, fear, spirituality, and difficult choices about cancer treatments in advanced stages of illness. Historical discrimination creates deeply rooted distrust, especially when that history includes betrayal of trust by health care providers.[38] In studies of general medical care, minority patients are more likely than whites to distrust health care providers and to perceive bias and disrespect in medical care.[39,40] In the North Carolina Prostate Cancer Outcomes Study, level of trust in physicians was associated with pursuit of screening testing by African American men.[41]

Overcoming Health Disparities: Health System Changes

Health disparities can be overcome. Unique forms of health information, such as decision aids, are effective at improving cancer care knowledge when tailored for African American audiences.[42] Working within cancer treatment centers, trained patient navigators or health advocates have been shown to improve utilization of cancer screening tests and timely follow-up of abnormal mammogram results for minority patients.[43-45] In a large program in the Emory health system, 125 trained health advocates and 20 navigators delivered breast cancer information to over 10,000 African Americans in a three-year period. In a cross-sectional analysis, investigators found a significant shift toward earlier stage breast cancer diagnosis which they attribute to this health system innovation.

Overcoming Health Disparities in Cancer Care: Community Partnerships

Community-based interventions allow cancer patients and their families to receive early information from a trusted source. Compared to whites, members of minority racial and ethnic groups often have stronger historical and spiritual ties to religious communities and to extended family as sources of comfort and strength.[46,47] Health education within churches has resulted in improvements in nutrition and dietary choices, screening, and chronic disease management.[48-53]

The lay health advisor model has been especially effective in socially marginalized and underserved communities as a means of empowering community members to help others access effective health care. Community leaders who are "natural helpers" within their social network are offered training in prevention or disease management.[54,55] Health advisors are encouraged to extend this new knowledge using group outreach presentations and individual counseling to promote health-related behaviors.[56] Lay health advisor interventions have demonstrated effectiveness to increase rates of breast cancer screening, sexually transmitted disease treatment, and chronic disease management in African American communities.[57-60]

Overcoming Health Disparities in Care for Advanced Cancer

These early tests of strategies to reduce health disparities in cancer have focused on prevention and access to early stage treatment; no research has yet tested interventions to bridge the divide in quality of care for advanced cancer. In North Carolina, investigators at the University of North Carolina are now working in an innovative community partnership in an effort to meet this need. Funding from the National Cancer Institute supported the development of a community health advisor training program to meet the informational and supportive care needs of African Americans with advanced cancer. Twenty-four health advisors received training and extended health information to 210 cancer patients and family caregivers.[61] With funding from The Duke Endowment, the Circles of Care project brings together partners from the Lineberger Comprehensive Cancer Center and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, the Rex Clinical Cancer Center, the Duke Institute on Care at the End of Life, the Community Health Coalition, and Project Compassion. Using the effective support team model of Project Compassion, Circles of Care will extend volunteer supportive team training to 120 African American volunteers in 20 support teams throughout central North Carolina.

Health disparities have been documented across the continuum of cancer care. Cancer center navigators and community outreach through health advocates and lay health advisors have helped reduce disparities in preventive services and early stage treatment. Compared to whites, African Americans and other minority groups continue to experience later diagnosis, more advanced cancer, and more severe cancer pain. Scientific research continues to examine biologic differences and implications for individualized cancer treatment. However, creative partnerships between community advocates and cancer care providers can create solutions for the social, informational, and communication barriers that contribute to health disparities. **NCMJ**

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Advocacy for Veterans within the Veterans Health Administration

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Our nation's 23.4 million Veterans are a special population with a unique set of experiences and needs. About 5.5 million Veterans receive part or all of their health care within the Veterans Health Administration (VHA) health care system. Traditionally Veterans seen at VHA facilities have been older, poorer, and sicker (more physical and mental health diagnoses), compared with the general US population.[1] The ongoing conflicts in Iran and Afghanistan, termed Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF), have added new Veterans to VHA's roles. These Veterans are, on average, younger but many suffer from multiple complex physical and mental health problems, including traumatic brain injury (TBI), amputations, burns, combat stress, and post-traumatic stress disorder (PTSD). Advocacy for individual patients trying to navigate health systems when they are ill is important in any health care system, no matter how good. Advocates have been a particularly effective way to protect and improve health care for both older and younger Veterans—Veterans who may be suffering from a variety of physical and emotional conditions and who have to negotiate often difficult paths within a large federal organization.

> *"Advocates have been a particularly effective way to protect and improve health care for both older and younger Veterans…"*

Veterans' advocacy efforts are provided by a range of organizations that include governmental agencies at the local, state, and federal level and nongovernmental groups, such as the broad array of Veterans' service organizations (i.e., American Legion, AMVETS, Disabled American Veterans, Paralyzed Veterans of America, Veterans of Foreign Wars, Vietnam Veterans of America, and many others). All these groups advocate for Veterans to ensure that they receive needed services and eligible benefits in a high quality, efficient, and timely manner. This commentary focuses on the clinical advocacy efforts being provided at the federal level within the Veterans Health Administration (VHA), part of the cabinet-level Department of Veterans Affairs (VA), and will also describe activities at the state level within North Carolina.

VHA is the largest integrated health care organization in the United States; in fiscal year 2008, it had 153 medical facilities and over 1,400 other sites of care, including community-based outpatient clinics, community living centers, Veterans Centers, and residential rehabilitation treatment programs.[2] VHA's mission is to honor America's Veterans by providing exceptional health care that improves their health and well-being. Along with providing primary and specialty medical care for all eligible Veterans, VHA offers a range of specialized programs that provide advocacy and care for specific groups of Veterans, such as female Veterans, homeless Veterans, those needing blindness rehabilitation, those needing readjustment counseling, and those at risk for suicide.

VHA's Patient Advocacy Program

In any health care setting, patient expectations are not always met. A patient may be upset about how he is spoken to or that he has to endure a long wait at the pharmacy, or he may disagree with the plan of treatment or may simply want to change providers. To ensure that all Veterans served in VHA facilities and clinics and their families have their concerns and complaints addressed in a convenient and timely manner, VHA initiated a formal Patient Advocacy Program.[3] Established in 1990, the program was based on the recognition

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that a consistent, organized approach to handle patient complaints and improve the system was desirable to better meet patient expectations. Over time, the patient advocate role has evolved from a primarily administrative position to one that involves being a facilitator, problem-solver, and change agent, an important element in the VHA's effort to provide world-class customer service.

Patient advocacy programs now exist at all VHA facilities, with each facility having at least one patient advocate available to each Veteran and his or her family. The primary role of the patient advocate is to manage the process by which Veterans register complaints about their care, ensure complaints are documented, track complaints in order to make improvements in care delivery, and work to resolve such complaints. For example, a facility identified an increasing level of patient dissatisfaction with having to wait up to two hours to receive medications. At the same time, pharmacists recognized the need for increased patient education to reduce medication errors. As a solution, the pharmacists' role was expanded to include a colleague during patients' clinic visits to review medications and provide education. While education was taking place, other pharmacy staff filled prescriptions, thus shortening the waiting time for patients.

Patient advocates interact with individual patients and families to resolve issues and ensure Veterans are aware of their rights and responsibilities related to their care at the VA. They continually solicit Veteran feedback about the complaint process and provide training to Veterans on how to use that process. Patient advocates also assist front-line clinical and administrative staff in resolving issues that occur at the point of service, often within an environment fraught with emotion. A Veteran may come to the advocate's office and describe a situation in which he felt he was treated rudely and disrespectfully in an outpatient primary care clinic. After apologizing to the Veteran on behalf of the facility, the advocate then shares the Veteran's experience with the clinic staff to help them be more aware of how their speech and behavior can aggravate an already-difficult situation.

Advocates offer Veterans a person who is passionate about providing the best care for individuals within a very large, often confusing and frustrating health care system. Many advocates have clinical backgrounds that help them better serve patients. When a Veteran complains that "no one is doing anything for my stomach pain" or that he "was not given any medication to make the pain go away," the advocate will review his medical record, ascertain whether anyone explained the diagnostic purposes of his tests in a way that he understood, and facilitate a meeting between the Veteran and the clinic nurse to see that the information is provided in a patient-friendly and supportive way. Patient advocates also provide assistance to patients who are not satisfied with their treatment plans by arranging for second opinions from different providers.

Advocates also work directly with service chiefs to facilitate resolution of problems that are beyond the scope of front-line staff. Helping patients assert their right to change providers when they are not satisfied with the care they are receiving is an example of a patient advocate's responsibilities. If the advocate notes that there are frequent change requests for a certain provider, the advocate may approach that provider's service chief with the information, so that the service chief can assess whether there is a need for the provider to be given opportunities to improve. At the facility leadership level, advocates present patients' perspectives on problems and make suggestions for improvement. By tracking and trending both complaints and compliments, advocates can identify system gaps and recommend needed improvements.

Patient advocates work with a number of program-specific staff in facilities, including OEF/OIF program managers, women veteran coordinators, and minority veteran coordinators to ensure these and other special Veteran populations have their concerns addressed and that system gaps between expectations and performance involving these Veterans has narrowed. This collaborative approach allows the VHA to identify the specific needs and interests of these special populations.

Advocating for Our Newest Veterans

The role of advocacy in patient-centered care is particularly salient when considering how best to provide health care for returning warriors while our country is still at war. Over 1.6 million men and women have served as part of the US all-volunteer fighting force during the past seven years, with most having been deployed to Iraq or Afghanistan.[4] Nearly 75% of troops have been deployed two or more times, moving through all stages of the deployment cycle, back to reintegration with family and community, then preparing again for service in a combat zone. Meeting the health care needs of this varied and mobile fighting force has required unprecedented collaboration between the VA, the Department of Defense (DoD), and state and community health organizations.

Beginning in 2003, the VA Secretary created several new positions to assist these Veterans and their families with coordination of care issues. The VA Liaisons Program currently includes 27 liaisons through the VA Office of Care Management and Social Work who facilitate the transfer of care from military treatment facilities (MTFs) to VA Polytrauma Centers or other VA facilities of soldiers suffering from serious injuries.[5] VA liaisons are integrated at MTFs, including two in North Carolina at Ft. Bragg's Womack Army Medical Center, to provide on-site consultation about VA resources and treatment options and to coordinate health care for service members as they transfer from DoD to VA.[6] They actively engage with the OEF/OIF care management teams at local VA facilities through the coordination of referrals for health care in collaboration with Veteran Affairs Medical Center (VAMC) OEF/OIF program managers and care teams and maintain involvement until health care is arranged and transfer is complete.

Another new position, the transition patient advocate (TPA), accompanies these Veterans as needed when they transfer to VA medical facilities and, once there, serves as the facility's point of contact to ensure that these severely-injured Veterans and their families have a personal advocate as they move through the VA system. These advocates help to smooth the often physically and emotionally difficult transition process. Sometimes the TPA may be found on the tarmac, welcoming home returning troops and providing a friendly face associated with VA. At other times the TPA may make home visits or assist a Veteran with transportation to important appointments, such as to his compensation and pension examination, perhaps after learning that the Veteran's PTSD and TBI symptoms have made driving impossible.

The VA health care system, like many others, is complex and can be difficult to navigate. For Veterans unfamiliar with the VA system and struggling with problems associated with combat trauma such as blast injuries, it can seem impossible. Symptoms such as memory problems, cognitive impairment, severe avoidance of trauma reminders which may include driving or crowds, may contribute to reduced ability to problem-solve and result in withdrawal to the point of social isolation and poor access to care. When combined with common readjustment issues such as insomnia, hypervigilance for danger, and hyperarousal, it's easy to see how frustration and anger disregulation may serve as further barriers to problem resolution. The TPA can provide a trusted familiar connection to VA services and support access to health care for returning injured Veterans and assist them with the transition to civilian life. TPAs also forge collaborative relationships with their counterparts in the National Guard, the transition assistance advisor (TAA), to provide returning Veterans with accurate information about benefits available to them through DoD and VA.

As the number of OEF/OIF Veterans seeking VHA health care increases, VHA facilities are striving to meet the challenge of ensuring that they receive necessary physical health, mental health, and advocacy services, while continuing to assure the needs of all Veterans are being met. A Combat Veteran Call Center Initiative began on May 1, 2008, targeting specific groups of Veterans, including those who have been discharged from the military but have not accessed VA health care. The goal is to remind Veterans of the services the VA offers and provide information or contact staff should they need or choose to use VA medical facilities.

Advocating for OEF/OIF Veterans in North Carolina

Advocating for OEF/OIF Veterans is especially important in North Carolina, which has the fourth largest concentration of active duty service members in the nation and hosts several major military bases for Marine, Army, and Air Force service branches.[7] The four VA medical facilities in North Carolina (Durham, Fayetteville, Salisbury, and Asheville) have developed a broad network of partnerships to better meet the health care needs of returning Veterans as they transition along the DoD/VA continuum of care.[8] All four medical centers have conducted "Welcome Home" events annually for the past two years, as mandated system-wide by VA. These events are geared specifically to OEF/OIF Veterans and family members. Representatives from a wide range of groups display information about their services, including VA, Vet Centers, state and local government agencies, Veteran service organizations, and community organizations. Veterans and family members are provided material on health care, health promotion and disease prevention, job services, and educational benefits. Many of these services may be unfamiliar to this new generation of Veterans and their families. National Guard service members and Reservists who were activated after August 1, 1990 and have served at least 90 days with receipt of an honorable discharge are potentially eligible for VA services. However, the VA has generally not been part of their military culture prior to the current conflicts. Reserve component troops have welcomed these tailored outreach and advocacy efforts, as reflected in the increased VA enrollment among returning National Guard and Reservists.

Because of the high prevalence of mental health concerns in returning troops,[9] the VA Mid-Atlantic Mental Illness Research, Education, and Clinical Center (MIRECC), headquartered in Durham, is focused on post-deployment mental health. MIRECC programs develop educational materials for Veterans and families to help them understand and cope with post-deployment challenges. Research studies investigate new treatments for PTSD, depression, and TBI, and search for genetic, medical, and psychosocial factors that could be associated with chronic adjustment problems and lead to more effective prevention strategies. MIRECC staff have collaborated with the North Carolina Area Health Education Center (AHEC) program to advocate for and disseminate a provider education curriculum tailored to the needs of returning service members. With support from the Citizen Soldier Support Program,[10] this curriculum for mental health professionals and primary care providers has been offered through a series of workshops across the state beginning in 2008. VA medical centers also provide OEF/OIF program staff at Post Deployment Health Reassessment events, which occur 60-90 days after return from combat deployment. These outreach efforts partner directly with DoD and National Guard/Reserves and help link returning Veterans with health care services instead of waiting for them to discover their options later on or when they are in crisis.

Partnering in Advocacy Efforts for Veterans

VHA's mission is to advocate for and meet the health care needs of all enrolled Veterans, from the few who are seriously injured to the many with less severe but still significant conditions. VHA recognizes that partnering with other agencies is essential to accomplish their goals. Communication with organizations serving Veterans and their families has never been more crucial. Thus, VHA is forming strategic partnerships to ensure effective coordination of care within VHA or to provide a "warm handoff" when necessary to community health care providers and other service organizations interested in meeting Veterans' needs. These partnerships may include assistance in finding state mental health or TriCare providers for Veterans' children or spouses or helping Veterans find out information about their military discharge. In this way, and the other ways described above, VHA is working to advocate for Veterans and to bridge the gaps in the system between national, state, and community levels of support. **NCMJ**

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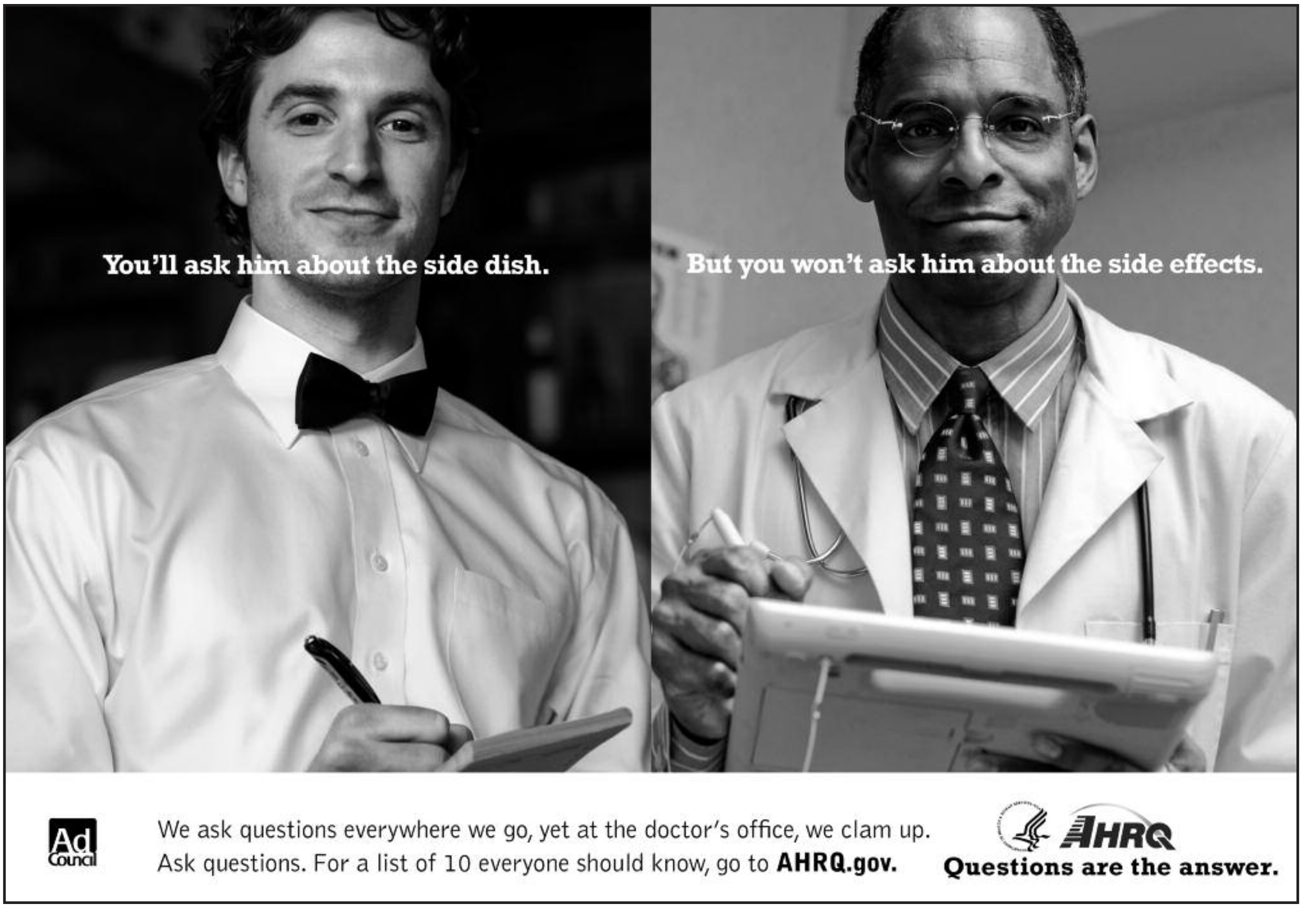

When the Patient is the Payer:

Consumer-Directed Health Care and Patient Advocacy

Joseph Coletti

Generally speaking, when a person uses someone else's money to buy something for another person, the purchaser does not think much about cost or quality. When that person uses someone else's money for himself, the purchaser cares a lot about quality and less about cost. When that person uses his own money for somebody else, he cares a lot about cost and less about the appropriateness of his spending. Only when a person uses his own money on himself do the incentives align for the purchaser to seek both low cost and high quality. It follows, then, that the best advocate for a patient is the patient himself or a trusted family member, and the best way to advocate for better care is to control the payment for care. This is the simple premise of consumer-directed health care.

With one-fifth of consumers now enrolled in some form of consumer-directed health care plan and trends continuing toward more consumer direction, it is worth examining this premise. Experience, budget constraints, and psychology offer reasons to expect better health results at a lower cost if patients can direct their own dollars and make their own decisions about their care. Before exploring those reasons, it is important to clarify what we mean by consumer-directed health care and how it differs from other options.

Distortions in the Health Care Market

As many as eight million people in North Carolina do not pay directly for their health insurance or health care. Medicare covers almost every North Carolinian over 65. Three-fifths of North Carolinians under the age of 65 get insurance through an employer, and one-fifth are enrolled in a government program such as Medicaid. The other one-fifth are either uninsured or purchase insurance on their own.[2] One-quarter of the uninsured are likely to be eligible for a government program.[3] With so many people covered by third-party payers, it should not be surprising that out-of-pocket costs have fallen from one of every two health care dollars spent in 1960 (47%) to just one of every eight today (12%).[4]

Arnold Kling labels the current system "insulation," not insurance.[5] When health care consumers pay 12 cents of each dollar for their health care, the care they purchase only has to produce a little more than 12 cents of benefits to be worth the perceived cost. If we had the same deal at restaurants, a $24 family dinner at McDonald's would cost less than $3. Dinner for two at Ruth's Chris Steak House would be about $12, but reservations would be impossible to get.

What is Consumer-Directed Health Care?

Consumer-directed health care is most closely associated with high-deductible health plans (HDHPs) and health savings accounts (HSAs). Other financing arrangements, such as flexible spending accounts (FSAs) and health reimbursement arrangements (HRAs), are also available. Each of these adapts, within the regulatory limits placed on it, to meet the demands of the market. But these plans are only half-measures to true consumer direction and each engenders criticism for how it currently functions. The legal restrictions on HSAs—tying them to certain high-deductible policies and placing severe limits on the amount an individual can contribute in a year—makes them unattractive and inappropriate for many who could otherwise benefit. The "use it or lose it" nature of FSAs can lead to wasteful expenditures as the annual deadline approaches. The inability of employees to contribute to their HRAs makes this vehicle less effective than it could be. Also, both FSAs and HRAs are not portable from job to job.

> *"…the best way to advocate for better care is to control the payment for care. This is the simple premise of consumer-directed health care."*

An important part of the solution to the above challenges would be to eliminate tax law provisions that date back to the

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1940s. These provisions give tax privileges to employer-sponsored insurance over individually-purchased insurance. A number of proposals from the left[6] and the right[7] would eliminate the tax disparity between employer-sponsored insurance and individual spending on health care. Any of these proposals, as well as the straightforward but politically difficult proposal to simply cap or end the tax break for employer contributions without offsetting the tax increase,[8] would put all health care dollars on equal footing.

Equalizing tax treatment, if it led people to purchase insurance in the individual market, would also provide more stable coverage for those in poor health who lose their jobs.[9] Only 9% of unemployed workers decide to continue their employer-sponsored insurance coverage, in part because of the cost.[10] Many of those 9% are likely to have a medical need, such as pregnancy, that exceeds the cost of coverage. Others may be more willing to take the risk of being uninsured in order to avoid high health insurance costs.

Beyond choice of insurer, consumers should also have equal tax treatment if they purchase health care on their own without insurance. My family has a high-deductible insurance policy that still covers too many things and is too expensive, but we use our health savings account to see a doctor who does not take insurance, so we file our own claims. Why should taxes on that choice and the resulting care depend on the type of insurance I purchase? It's possible that removing the tax penalty for directly purchasing care can improve the doctor-patient relationship while eliminating dependence on employers and insurers.

Three Main Reasons to Select Consumer-Directed Health Care Plans

Reason #1: Experience in other areas

Only in education have government regulations and tax policy limited consumer choice as much as in health care. In no other industry do third-parties—whether government, employers, or insurance companies—pay most of the cost. But even this distortion is not found everywhere within the health care industry. Dentistry, cosmetic surgery, laser eye surgery, cash-only practices, and medical tourism all rely more on consumers who pay for their own treatment. In these areas, unlike in the majority of health care, prices have fallen while quality has improved. Consumers or their family members act as their own advocates and therefore pay attention to the value they get for the dollars they spend.

Duke law professor Clark Havighurst has argued that significant changes in health care have occurred precisely in those areas where consumers spend their own money and direct their own care. That is, practices that meet the needs of those with high-deductible plans or no insurance have been the most innovative.[11] In addition to the practices listed above, consider the creation of convenience clinics or the proliferation of $4 prescriptions. Few people with more traditional copay-only insurance policies demanded these innovations, although they have clearly benefited from their use.

When consumers are in control of their own dollars, they seek more information and find cost savings that benefit everyone. For example, Aetna found that consumers with HSAs were similar in age and family size to those with more traditional plans but accessed online tools more than twice as often and changed their health care consumption in such a way that Aetna had savings equivalent to "$1 million per 1,000 employees over a three-year period while still maintaining quality care."[12]

Markets create a need for information. When consumers control how, when, and where they spend their health care dollars, they care more about cost and quality of care. Consumers have not been in a position before now to demand information because cost control is not important under indemnity plans and choice is limited under HMO and PPO plans.

Reason #2: Budget constraints

Health care is a scarce resource. The supply of doctors is not infinite nor is the time or financial resources of doctors, patients, and those who pay for care. As a result, care must be rationed and somebody must decide what care is not worth providing or consuming. When a state or federal government decides, it can ration care directly on the demand side by denying treatment. More often it relies on low reimbursement rates for Medicare or Medicaid, strict licensing laws, certificate of need rules, preferred drug lists, and other regulations to limit the payment for or supply of care.

Private insurers and Medicare presently look to pay for performance, evidence-based medicine, or comparative-effectiveness research to help determine what care is worth purchasing. While established best practices can be overturned with new research, formal rules and regulations based on existing practices may not change as quickly. In addition, there are always outliers who do not respond or who have adverse reactions to established protocols. Finally, individual risk preferences vary so that one person may prefer a less invasive procedure that treats most of the problem to a more invasive one that treats all of it.

Much of the empirical research into consumer-directed health care has focused on whether persons enrolled in consumer-directed plans can afford coverage or if they delay care. No research exists on actual health outcomes tied to these determinants. The closest we have is the RAND Health Insurance Experiment,[13] which found that patients with higher deductibles delayed treatment and took other cost-saving steps, but had similar health outcomes as patients with lower deductibles who used more care. Within Medicare, the Dartmouth Atlas Project[14] found that costs in the top-spending regions were 30% higher than in low-spending regions, again with generally similar outcomes.

Reason #3: Human psychology

Consumer-directed health care protects individual risk preferences and provides the best way to accommodate new information in health care decisions. Just as consumers will seek information if they have control over a decision so, too, will they have more incentive to correct a bad decision they made.

Consumers will make mistakes about care, even if they get the best information and advice. It happens. In most cases the damage of that mistake will be limited to the person who made the mistake. The damage from mistakes by insurance companies, employers' human resource staff, and government regulators, however, can hurt dozens, hundreds, or even thousands of people. In general the person making a mistake can see the effects more quickly and act on them sooner than can an insurance company or a government official.

Imperfect people with imperfect information also make company and government policies. Those policies affect more people, have more ambiguous impacts, and are harder to change. Moreover, an examination of federal safety regulations found that there was no pattern to the balance of risks and benefits allowed. In the case of airbags, regulators even mandated changes with minimal benefits and significant risks.[15] In short, regulators, employers, and insurance claims adjusters do not have the same incentives as consumers themselves to make the right decision.

Difficult Patients or Demanding Consumers?

Moving to consumer-directed care could also change the attitudes of providers toward their patients. Anecdotally, many doctors consider patients who ask questions and do their own research "difficult." These patients may challenge their diagnoses, request the newest drugs they have seen advertised, or ask questions about something they read online. They may go to a doctor halfway across the country who specializes in conditions such as theirs.

Sometimes the patient is wrong and, for example, his self-determined dosage schedule for insulin does not help him control his blood sugar. Other times the patient is right and, with the right treatment regimen, she can bear children despite scleroderma.[16] The important thing is that the provider-patient relationship should be collaborative, with proper deference accorded to both the medical training of the professional and to the patient's personal experience and preferences.

Unfortunately, most physicians have little time to talk with their patients. Insurance companies will pay for drugs and tests, but not talking time. The reimbursement rates, payment delays, unpaid invoices, and administrative headaches of Medicare and private insurance put more pressure on doctors to churn through dozens of patients a day.

Insurance companies have their own voicemail maze for patients to navigate, so it is difficult to rely on them for advocacy. On top of this, a patient's employer pays the premium in most cases, not the patient herself. Elected officials only have so much leverage over government health care bureaucracies and none at all over providers themselves.

That leaves the patient. Consumer-directed health care can give patients leverage with their employers, doctors, and insurers. That some consumers have been unhappy with their consumer-directed health plans should not be surprising because some of the decisions to adopt such plans are made by employers and so are subject to the same pitfalls described above. When patients control their own spending, however, they become their own advocates. They no longer have to seek permission and fight on two or three fronts—with the doctor about a treatment plan, the insurance company or government about what was or was not covered, or the employer about the poor plan design and high cost of the insurance.

To paraphrase from another industry: when doctors and insurers compete for your business, you win. **NCMJ**

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Legal Advocacy for Health Care and Health Insurance Issues

Edward G. Connette, JD

Patients, physicians, providers, payers, and payees—like peas in a pod, we all participate in our health care system, and we all have our personal stories to describe how that system works. Dr. Atul Gawande, currently one of our most astute authors on health care issues, describes the complex health system with stories. In a recent *New Yorker* article, he wrote of his experience as a surgeon in Massachusetts, the first state since Hawaii to enact legislation to assure universal access to health care. He noted that the majority of Massachusetts's citizens were very satisfied with the program and would not go back to the old system:

> I'm among them. For years, about one in 10 of my patients—I specialize in cancer surgery—had no insurance. Even though I'd waive my fee, they struggled to pay for their tests, medications, and hospital stay... For the past year, I haven't had a single Massachusetts patient who has had to ask how much the necessary tests will cost; not one has told me he needed to put off his cancer operation until he found a job that provided insurance coverage. And that's a remarkable change: a glimpse of American health care without the routine cruelty.[1]

Like every reader of this *Journal*, I can regale you with my personal health care stories. I also have the stories of my clients. I am a lawyer. I help people whose health benefit plans have denied coverage for potentially life-saving medical treatment. The patients who come to me have experienced the health care system at its worst. Their stories, like Dr. Gawande's and your own stories, can guide us in making informed choices as we seek to improve or reform our health care system.

I have seen the evolution of our health care system through the eyes of my clients. In the 1980s I watched health insurance companies and plan administrators begin working in earnest to curb rising health care costs. They worked quickly, establishing networks of preferred providers and HMOs, negotiating broad provider discount rates, and implementing complex, graduated scales of patient copayments, deductibles, and policy caps. Physicians and community practice groups, accustomed to traditional fee-for-service reimbursement models, were slow to react. Consumers reacted much more slowly. Physicians, patients, consumers, and lawyers all were accustomed to traditional notions of health insurance. A "self-funded" health *plan* with something called a third-party administrator was an alien concept. ERISA sounded like the capital of an underdeveloped nation.

"Until 1989, I had never heard a client complain about a health benefit coverage denial. Then, suddenly, the doors burst open, and for the next few years hardly a day passed without someone calling for help with a health benefit issue."

Many of those early cost-cutting initiatives were primitive but well-intentioned. Some have become routine components of our health care system. Other cost-saving measures were much cruder. Treatment for many patients was senselessly delayed or denied. People died.

Until 1989, I had never heard a client complain about a health benefit coverage denial. Then, suddenly, the doors burst open, and for the next few years hardly a day passed without

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someone calling for help with a health benefit issue. Typical were the patients suffering from stage III or IV breast or ovarian cancer, seeking admission to hospitals at Duke, UNC, Wake Forest, or East Carolina for enrollment in promising treatment protocols using high dose chemotherapy supported by autologous bone marrow cell transplants. Treatment centers would not admit these women without precertification of insurance coverage.

Many insurance companies considered the treatment to be "experimental," "investigative," or "not medically necessary." These benign sounding words, buried deep in the health plans of the day, had been inserted to bar insurance coverage for the more outlandish forms of quackery, such as the laetrile treatment[a] for cancer that lured desperate patients to places like Mexico in the 1970s. Suddenly, these loosely defined terms were being used to exclude coverage for costly treatment at the nation's leading hospitals.

Within the insurance companies, the benefit decisions were often being made by unqualified personnel. Coverage decisions for complex cancer protocols were sometimes made by the same claims examiners who reviewed and approved coverage for sutures and flu shots. When they sought independent review by oncologists or other medical specialists, they did not even know what questions to ask.

By the early 1990s, the challenge faced by health plan administrators in making informed, rational coverage decisions was compounded by the dramatic transformation of standard treatment options, particularly in the field of oncology. While insurance companies were accustomed to determining standard treatment modalities based on peer-reviewed medical literature, cancer researchers were developing a body of data and treatment protocols that seemed to change weekly, sharing their research using this new thing called the internet.

The patients' stories were compelling. Without insurance coverage, they could not be admitted for treatment. Without treatment, they would die. The coverage denials always seemed to occur during that narrow time window of remission where the patient could best tolerate a stem cell harvest followed by the high dose infusion of chemo. Time was critical. My strategy was to fax hundreds of pages of patient medical records, supported by medical literature and the details of the treatment protocols, to the insurance company, with an urgent letter asking for them to allow coverage immediately or deal with me going before a federal judge to obtain a temporary restraining order. A handful of lawyers around the country were doing similar work. We shared court rulings and other information by fax.

Much of our current jurisprudence governing health benefit denial issues was shaped by this early stem cell litigation. Many of the cases were decided following an expedited preliminary injunction hearing, with little or no opportunity for the parties to gather complete information and fully develop their presentations. A patient's life hung in the balance, and all the parties to the litigation were mindful of the urgency and gravity of the decision to be made by the judge. It was high drama, but it was a terrible way to make health benefit determinations.

Fortunately, we have enjoyed a decline in the number of health benefit claims being litigated over the past 10-15 years. I attribute this to several factors:

- Health plan administrators have developed much more sophisticated processes for analyzing the merits of benefit claims for cutting-edge medical treatment. Today, valid claims are more likely to be allowed, and questionable claims are more difficult to challenge.
- Health plans have developed provider discount arrangements with research hospitals and "centers of excellence," which enable more patients to participate in research protocols that once would have been off limits.
- Health plan language is drafted much more explicitly today. In most situations, the language of the plan itself is clear enough to support granting or denying benefits.

The role of lawyers in representing patients with health care access issues is shrinking for additional reasons. First, the cases usually are governed by ERISA, which gives deference to the benefit determinations of the health plan and comes packaged in a complex web of US Labor Department regulations that are incomprehensible to most attorneys. Many cases today involve complex medical issues where coverage may not be clear cut, and in those cases the health benefit administrators are given broad latitude to make coverage decisions. In most cases under ERISA, the patient must show that the plan administrator "abused its discretion" in denying coverage.[b] The administrator does not have to follow the recommendations of the patient's treating physician as long as there is some reasoned, principled basis to support the decision.

The final reason for shrinking attorney involvement may be the most important: we have witnessed the development of a network of highly-trained non-attorney "patient navigators" who typically come from nursing, medical claims processing, or insurance backgrounds. They talk the talk, and they have an uncanny ability to know the secret, direct telephone number of just the right person inside every health benefit administrator's shop. They perform miracles, and they do it quickly, usually at no cost to the patient. A prime example is the team of patient

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[a] Laetrile is a substance that commonly is derived from apricot pits. It is related chemically to amygdalin and sometimes is marketed as "Vitamin B-17." In the 1970s, it became known as a treatment option for cancer even though it had no proven clinical efficacy and was never approved by the FDA. Cancer patients seeking laetrile treatment typically went to private clinics in Mexico to receive the substance.

[b] This standard of review—the amount of deference given to plan administrators—is a threshold consideration in every ERISA benefits case. A good starting point for understanding the issue and its importance is a recent US Supreme Court decision, *Metropolitan Life Insurance Co. v. Glenn*, ---U.S. ----, 128 S.Ct. 2343, 171 L.Ed.2d 299 (2008).

Patient Advocate Foundation:
Partnering with Patients and Physicians to Solve Access Issues

Nancy Davenport-Ennis

The Patient Advocate Foundation (PAF), the leading direct patient assistance organization in the country, was established in 1996 to provide individualized, direct assistance to chronically and severely ill patients facing access to health care challenges. PAF's professional staff works with patients who are fighting to gain and/or maintain health coverage; struggling to resolve reimbursement and billing problems; and wrestling with medical debt crisis and job retention issues. Through its professional mediation and arbitration services, the Patient Advocate Foundation seeks to safeguard patients through effective mediation, assuring access to care, maintenance of employment, and preservation of their financial stability relative to their diagnosis of life threatening or debilitating disease.

PAF also facilitates the patient-physician relationship by assisting patients in resolving pre-authorization appeals, coding and billing issues, and coordination of benefit services. Additionally, PAF expedites Social Security Disability Insurance applications and Medicare and Medicaid applications. PAF partners with physicians to encourage patients to comply with their recommended protocols to assure the greatest benefit in disease management.

According to recent estimates, approximately 1.5 million of North Carolina's 8.9 million residents (more than 15% of the state's population)[1] do not have health insurance. Of these uninsured North Carolinians, nearly 91% will not qualify for Medicaid support, leaving them with few available options for accessing vitally needed health care.

Last year, PAF received more than 9.5 million online inquiries seeking information, including 239,264 from the state of North Carolina. Of this number nationally, 48,860 became full patient cases requiring professional negotiation and mediation to achieve resolution; these involved communications made by PAF staff on behalf of a patient in order to reach positive resolution. Of those patients served, 65.3% had medical debt issues resulting in loss of access to health care. Of that population, 56.5% had debt issues related directly to the patient's medical care, not lifestyle choices. Furthermore, over 93% of patients reporting medical debt as their primary issue were insured.

PAF services include:

- Mediation and arbitration services to help patients negotiate access to medical devices, surgical procedures, medications, clinical trials, and complex therapeutic protocols
- Negotiation of access to charity care at hospitals
- Copayment assistance for medications
- Procurement of medical write-offs for treatment services
- Negotiation of transportation and lodging for patients who must travel for treatment
- Negotiation of both public and private health insurance coverage through COBRA, Medicaid, Medicare, and state high risk pools created January 2009
- Negotiation and identification of resources for cost of living assistance, including rental and mortgage delinquencies; eviction and foreclosure problems; food and nutritional needs; and utility assistance
- Provision of assistance to expedite enrollment into and appeal negotiations with Social Security Disability Insurance; Supplemental Security Income; Long Term Disability and Short Term Disability; and the complete compliment of Federal, State, Local, ecumenical and social resources

For more information, contact the Patient Advocate Foundation by calling 800.532.5274 or online at http://www.patientadvocate.org.

Nancy Davenport-Ennis is the founder, CEO, and president of the Patient Advocate Foundation.

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[1] Henry J Kaiser Family Foundation, 2007 State Health Facts.

navigators working with the Patient Advocate Foundation (PAF).[c] The PAF staff of trained, professional case managers fields calls from patients throughout the United States and help them obtain access to available coverage under private health plans, government or military plans, Medicare, Medicaid, or charity waivers. (See the sidebar on this page for more information on the Patient Advocate Foundation.)

Other organizations of patient navigators operate from

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[c] Disclosure: I serve as an unpaid volunteer on their Executive Board of Patient Advocate Foundation and its related policy organization, the National Patient Advocate Foundation, and acted as its board chair for the past two years. For more information on these organizations, visit www.patientadvocate.org and www.npaf.org.

various platforms throughout the country. Here in North Carolina, the Managed Care Patient Assistance Program, within the Consumer Protection Division of the Department of Justice, offers help to patients facing health benefit problems. At the national level, the federal Patient Navigator Outreach and Chronic Disease Prevention Act of 2005[d] was passed to provide funding to organizations that offered patient navigator services. To date, funding authorized for the program has been minimal. As of this writing, it is expected that the current administration will seek $9 million in funding in the 2009 budget.

What is a patient navigator? The challenge for patients is that there is no standard definition. There are no minimum standards of education, training, and experience. Nor is there any form of certification or accreditation for patient navigators. Today, the job title of "patient navigator" is ubiquitous. They are found working in hospitals and community practices, insurance companies, pharmaceutical companies, and a wide range of nonprofit and health advocacy organizations. Some are social workers. Others come from managed care or patient billing and accounts backgrounds. Many are former patients with good hearts but little training. At a minimum, the patient advocacy community needs to develop education, training, and experience standards for patient navigators. Ideally, a national certification standard will emerge, with additional criteria for ethical behavior, continuing education, and supervision by an accrediting organization.

With the evolution of experienced patient navigators, I believe the role of lawyers in challenging health benefit denials will continue to shrink. As our health care system continues to evolve, so also will the role of attorneys representing patients. For example, when an employer withholds health insurance premiums from workers' paychecks but allows the insurance to lapse, the employees will need lawyers.

Embedded within the system are more insidious pitfalls for patients where lawyers will be needed. For example, the out-of-network "usual and customary" reimbursement rates for treatment services followed by virtually all large plan administrators are set by Ingenix, a wholly owned subsidiary of UnitedHealthcare. As every patient knows, these reimbursement rates are unconscionably low, but it would be virtually impossible for any single patient to challenge the reasonableness of those rates.

On January 13, 2009, New York Attorney General Andrew Cuomo announced a settlement with UnitedHealthcare that will require the insurer, among other measures, to pay $50 million to establish a new, independent database run by a qualified nonprofit organization. This nonprofit will own and operate the new database, and it will make all decisions regarding compilation and interpretation of cost data. To help patients, the nonprofit will make reimbursement rates public on a website where patients can find out in advance how much they may be reimbursed for common out-of-network medical services in their area.[2,3] The New York attorney general's investigation of other insurers is continuing, but we can expect to see more individual and class litigation by patients challenging the Ingenix-generated reimbursement rates and seeking recovery of underpayments.

This commentary is quite different from what I would have written in 1992, 2000, or even last year. It differs from what I might write a year from now. In my earlier years, I regarded insurance plan administrators as the enemy. I now recognize the pioneering work they have done in trying to manage health care costs. Indeed, the largest single barrier to health care access for all people is its cost. While I applaud the evolution of new pharmaceuticals, I am terrified by what their cost will do for the system as a whole. My doctor friends' practices have been radically transformed by the evolution of managed care. I hear their stories and worry that they will burn out, become disillusioned, and leave practice. I worry about the challenges of attracting and retaining physicians in front-line community family practices and internal medicine. These trusted family doctors have been recast as "primary care physicians," but they still are the soul of our system.

We all share responsibility for creating affordable health care that is accessible to all. We all are patients, and we all regard ourselves as patient advocates. "I am a patient advocate" is one of the most common declarations I hear. Physicians, nurses, hospital and medical practice administrators, third party administrators, pharmaceutical industry workers, attorneys—we all say it and believe it. Let's use our shared commitment to quality patient care to forge a better system. **NCMJ**

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[d] HR 1812.

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Health Reform Advocacy:
Change Brings Opportunity

Adam Searing, JD, MPH

Advocating for better health care has a long history in North Carolina. Today, new technologies are providing substantially different opportunities to create change. Advocates who wish to successfully reform health policy both nationally and in North Carolina should look to the past while considering the future.

The History of Health Advocacy—Two Examples in North Carolina

In North Carolina in the 1940s a sustained effort was made towards achieving affordable coverage for everyone under the banner of the "Good Health Plan." With an over 50% rejection rate of North Carolina draftees due to poor health, prominent doctors, public and private universities, health professionals, and politicians came up with a strategy for moving North Carolina forward. Governor and later US Senator Melville Broughton said in describing the plan, "The ultimate purpose of this program should be that no person in North Carolina shall lack adequate hospital care or medical treatment by reason of poverty or low income."[1]

Support from political leadership and such North Carolina legends as Frank Porter Graham was key to the effort. Graham and others traveled around the state to drum up support. Enlistment of celebrities like Kay Kyser, Frank Sinatra, and Dinah Shore also increased the public's interest. However Good Health Plan advocates faced a major hurdle to achieving the primary aim of universal coverage—there simply weren't enough doctors and quality hospitals in the state to provide state of the art medical care to everyone, even if people could afford it. Therefore, much of the lobbying push for the plan centered on expansion of a medical school and hospital (ultimately at the University of North Carolina at Chapel Hill) and expansion of other medical facilities.

Despite the rhetoric, the Good Health Plan was ultimately an advocacy effort that, while it drastically improved quality and access to care, failed to achieve its primary purpose. North Carolina had the will to build health care institutions and expand medical, dental, and nursing schools, but not to guarantee universal coverage. Advocates ran up against the already strong opposition of doctors to larger government participation in health coverage plans—the socialized medicine objection—and a state that was still largely poor. The top-down nature of the advocacy effort probably contributed to the failure to achieve the coverage goal as well. Once the professional schools and medical facilities were on the road to expansion, some of the strongest advocates for change dropped their pressure, feeling the expansion of the training pipeline was enough.

In 1993, 50 years after the Good Health Plan effort, North Carolina had changed drastically. Not only were many of the facilities envisioned in the Good Health Plan constructed, but some had become nationally-renowned hospitals and medical schools. North Carolina had become a much wealthier state—at least in its most urban areas. Poverty had declined—again disproportionately in the urban areas—and North Carolina was in danger of losing its dubious distinction as the state with the highest number of outhouses in the country. Establishment of Medicare and Medicaid by the federal

> *"Health reform is possible and, given rising health costs and the state of the economy, necessary. New media techniques and tools can give health advocates an edge to overcome some of the barriers of past reform attempts."*

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government combined with state Medicaid participation and expansion to push down the uninsured rate to 15% of North Carolinians (1.1 million people).[2]

Nationally and at the state level, the year 1993 seemed ripe for another push at reform and consequently the General Assembly established the North Carolina Health Planning Commission. The Commission was charged with "developing a universal health care program to provide all North Carolina residents access to quality health care that is comprehensive and affordable."[2] The Commission gathered some of the most prominent and active individuals in the state interested in health care issues. However enormous amounts of work in 17 committees and subcommittees failed to produce a clear plan for universal coverage in North Carolina; there were serious disagreements over financing and the type of reforms that should be proposed.

Unlike the Good Health Plan effort, from 1993-1995 the political leadership of the state was not enthusiastic about the Planning Commission's efforts. Lacking not only broad public support but also strong political support, the Commission dissolved without sparking significant change. The charge of the Commission, to expand health coverage for largely lower-income state residents, also didn't include the bright new major public facilities that attracted many advocates of the Good Health Plan.

In the end, neither of the two biggest state-initiated efforts in the 1940s and the 1990s to guarantee affordable coverage to all was successful. The biggest factor in both failures was the lack of strong and continuing public support for truly affordable health coverage for all. With no broad base of public support for the changes needed for reform, strong special interest groups (physicians in the 1940s and the insurance and pharmaceutical industries in the 1990s) were able to prevail and block major change.

Other outside factors also played a major role in diverting North Carolina from the goal of universal coverage. National pushes for health reform played a dual role, by diverting the state from efforts to expand coverage based on the belief that national reform was the most effective solution. Each failure of national health reform then reverberated at the state level, dampening the desire for change.

Since the 1993 effort, health advocacy in the state has had less ambitious aims. Preservation of coverage under public programs and in nonprofit health insurers and institutions has been paired with efforts at improving quality, encouraging preventive care, and controlling costs. The most significant expansion of access—the federal/state children's health insurance program (SCHIP or Health Choice in North Carolina)—is largely funded federally and has been closed to new children in North Carolina at least once. Beyond SCHIP little appetite has been shown by either the political leadership or the public for any sort of broad expansion of health coverage in North Carolina over the last 15 years.

Technical Change Brings Opportunity

The technical methods and tools of advocacy have changed drastically in the last decade. These changes can provide an opening to overcome the roadblocks to reform experienced by previous major health advocacy efforts.

Extensive use of email newsletters has enabled broader and easier communication with members of advocacy organizations, the press, and the public at large. Increasing access to the web has meant information travels much more freely. Articles and opinion pieces formerly read by the readership of only one publication can now be distributed widely. Organizational and individual creation of news and opinion on blogs provide an outlet for enormous amounts of information and commentary from every type of advocate and interested party. Most recently, increasing broadband access coupled with the emergence of video-sharing websites like YouTube has enabled activists and politicians to speak directly to the public in ways that simply weren't possible even three years ago. Finally, social networking websites like Facebook enable quick propagation and sharing of news, video, comments, and activities between fast-growing groups of people and organizations.

This explosion in the ability to communicate in new ways and new formats directly with members of an advocacy organization and the public at large has another major component: it is not a one-way street. Opportunities to post on blogs, answer the authors of newsletters, comment on mainstream news stories, post response videos, and generally jump into the information explosion have made activists out of many people. With public interest in health care reform rising, these new media formats are creating new ways for the public to band with traditional health advocates and work together for change.

The Way Forward

Health advocacy in North Carolina's second 21st century decade will be in some ways much different than previous efforts. Although one important component will remain the same—the effort to involve as many individuals as possible through outreach efforts—the techniques and methods will be very different. A key part of this difference will be the attempt to win the "battle of ideas." This is the struggle to define the debate around the health issue in a way that moves the public towards the idea of affordable health care for everyone. Health advocates can make use of this technology to overcome, at least in part, the huge advantages enjoyed by powerful health care interests that helped doom the previous two major efforts at health expansion in North Carolina. There are three parts to this strategy:

1. **Blogs**
   Increasing use of blogs established by health advocates as a go-to source for opinion, debate, and information is critical. However, a blog is only as effective as the number of people who actually read it. While there are many interesting and

well-written blogs, this is no guarantee of success in attracting readership, which is what truly helps advance advocacy goals. Blogs on health care issues must be timely, informative, amusing, well-written, and consistently published. New information must be provided as frequently as possible. Ideally this would be every hour or two, but at the very least, several times a day.

Well-read blogs can also be a portal for the public to obtain documents and other information that would not be published or available anywhere else. For example, background documents and information referenced in a news story can easily be made available through links on the blog, adding credibility to criticism and favorably framing the debate.

A blog can also function as a place where news stories are written and broken and not just a collection of commentaries on the news of the day. This is becoming especially important as traditional news portals in the mainstream media continue to narrow coverage and cut costs. When major news outlets no longer have staff dedicated to reporting health issues, room exists for health advocates to investigate and break news themselves. Advocates obviously have their own agendas and resource limitations as to how and what stories they will tell, but the alternative, increasingly, is no coverage at all. Depending on availability of resources, advocates may want to dedicate significant staff time to reporting roles that were traditionally a function of the mainstream media.

Another emerging issue of importance in this area is the increasing connection between mainstream media sources and the health industry. Just in North Carolina, two major media outlets—the state's public radio network and the state's major newspaper—have established business relationships with the health industry that could present the appearance of a conflict of interest in reporting on health issues.[a] A blog can function as a media watchdog and an alternative method for advocates to get stories out that might not otherwise be covered.

2. **Video**

This is the emerging new phase in health advocacy strategy and is absolutely critical to future success. The same information, however interesting, informative, or incendiary, often produces much more interest and reaction when conveyed in a video rather than written format. Campaign-produced video was a critical component of the 2008 national presidential campaign and will increasingly be used in policy campaigns, both nationally and in North Carolina. For state-level politicians, this is likely to be a shock. For health advocates, this is a significant opportunity. For years, state-level politicians have enjoyed relative immunity from scrutiny over their words and comments made in more obscure legislative committees and budget debates. Now, however, public comments on mainstream television and in other formats from powerful players both in politics and in the health industry are fair game for advocates.

The technology to record, combine, and use these comments, contrast them with more recent comments from the same people, and provide a health advocate's own views of what others are saying is now relatively cheap and easily available. Any successful health advocate will increasingly make extensive use of video to supplement and enhance his or her other efforts.

3. **Broader Distribution of the Written Word**

The traditional way to win the battle of ideas—publication of extensive written reports and wide media distribution, including radio, television, and mainstream print outlets—is as important as ever. Look at any successful policy or advocacy organization and that organization has inevitably produced a wide range of reports and commentary on the issues important to that group. The traditional route is to draft a report with enough new information to hopefully interest the media, issue a press release or hold a press call or conference, and hope that reporters in the mainstream media pick up the information.

This is simply no longer enough. First, with the rush to new media, health advocacy organizations must not lose sight of the first priority—whatever they produce must be something people actually want to read. This means writing and facts that capture the public attention and focus debate on a particular issue. Second, the speed at which media moves necessitates a shift to shorter, more focused, and more frequent reports and commentaries. A weekly op-ed sent out around the state to smaller papers regarding health issues is effective. Appearance on radio and television to discuss recent issues and reports—prompted by the organization's recent writing on those same issues—is also effective. These longer reports and commentaries can mesh with the more up-to-the-minute coverage on the organization's blog and website.

Back to Basics

Winning the "battle of ideas" is still only winning half the war. While increasing sophistication with new media techniques and a move to breaking stories rather than just commenting on events will serve health advocates well, there is also a necessity to go back to the type of public outreach that has always been important in any political and policy campaign.

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[a] In 2008 WUNC radio co-produced the Blue Cross and Blue Shield of North Carolina corporate foundation's audio-based annual report. In 2009 the Raleigh *News and Observer* is publishing a subscription state health political newsletter written by Harry Kaplan, a lobbyist with health industry clients including the NC Association of Health Plans, Novartis, Purdue Pharma, State Farm Insurance, and MedSolutions.

State legislatures are often extremely responsive to business interests, regardless of which party is in power. In any state, the health industry makes up a significant part of the state business community and consequently has enormous power. North Carolina is no exception. Health care interests from insurance companies to state provider associations and the burgeoning pharmaceutical industry hold sway over much of the health care debate that takes place.

This makes it all the more important for health advocates to focus on the most basic of organizing strategies: talking to the people "back home" and getting them the information and resources they need to be effective advocates in their own right. As health costs skyrocket and people lose coverage, the interest in any group presenting solutions around health care reform is growing. This is another opportunity for health advocates. Community groups who perhaps might not have been interested in health reform before are likely to be interested now. Working with groups that health advocates might not have thought of previously as allies is especially important.

Building a network of activists, especially in the rural and poorer areas of the state, is a challenge. Focusing on groups that are already meeting about other issues is one way to tap into community organizations that already exist. Working with state groups who already have chapters that meet regularly around the state is another. Whatever method is used, health advocates will have to devote substantial time to this work.

Health reform is possible and, given rising health costs and the state of the economy, necessary. New media techniques and tools can give health advocates an edge to overcome some of the barriers of past reform attempts. Put these new approaches together with the basics of advocacy—the involvement of people all around the state—and the possibility of real reform will be more likely than ever. **NCMJ**

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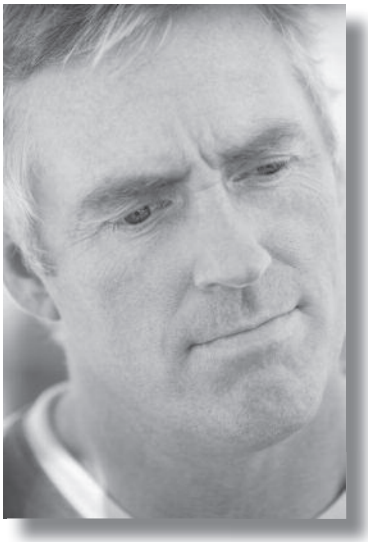

Media Advocacy:
A Powerful Tool for Policy Change

Ann Houston Staples, CHES

For many years it was illegal in North Carolina to "knowingly" sell tobacco products to minors. This wording made the law unenforceable. State law did not require merchants to check identification, and merchants could only be charged when they "knew" the purchaser was a minor.

This situation changed in 1997, thanks to a campaign to educate the public and decision-makers about problems with the law. Following this campaign, the North Carolina General Assembly passed legislation to stiffen fines for selling tobacco products to minors and made enforcement more likely by removing the word "knowingly" from the law.

The problems with the law and the state's high teen tobacco use rates were highlighted in a January 1997 investigative series published by *The Charlotte Observer* called "Carolinas youth: Sold on smoking."[1] This four-day series featured stories from across the state. It included eye-opening photos of teens lighting up and dipping, interviews with teens, and highlights on legislators and lobbyists on both sides of the issue. An editorial and an editorial cartoon called for the law to be changed and enforced. The series was distributed as a reprint to members of the North Carolina General Assembly.

> **"In practice, media advocacy is the act of strategically mobilizing community interest in a problem and its solutions."**

While the media and policy advocacy efforts of many organizations and individuals contributed to the passage of the teen tobacco sales law, the series and its reprint had a significant effect, according to leaders in public health. "Thanks to media advocacy efforts, reducing youth access to tobacco was one of the first policy changes our state embraced after the formation of the state's tobacco control program," said Sally Herndon Malek, MPH, head of the Tobacco Prevention and Control Branch of the North Carolina Division of Public Health.

For as long as there have been journalists there have been advocates using its pages to promote policy change. From Benjamin Franklin's "Silence Dogood" letters[2] to current legislative fights over funding, where there is the press, there are advocates strategically using the press to make changes in their communities. In his book, *Media Advocacy and Public Health*,[3] Lawrence Wallack, then a professor in the School of Public Health at the University of California, Berkeley, described how advocates use their knowledge of the news business in combination with their passion to change their communities. A later book, *News for a Change*, is a how-to guide on planning and carrying out media advocacy interventions.[4]

Media Advocacy Defined and Described

Formally defined, media advocacy is the "strategic use of mass media for advancing a social or public policy initiative."[5] Media advocacy gets the community involved in defining its problems and identifying the policy changes that could address those problems in ways that change the context in which people make decisions regarding their health behaviors.

Media advocates do some of the same things any public relations experts might do, including publicizing events, writing letters to the editor, and releasing data to the news media, but they do them in a more focused and strategic way, with a clear goal of policy change.

In practice, media advocacy is the act of strategically mobilizing community interest in a problem and its solutions. First, an issue appears on the community's radar screen and is seen by some in leadership positions as important. Second, a language develops around the problem, including common knowledge about the cause of the problem, who the local experts are, who is responsible for solving it, and what change or policy is likely to address it.[6] Third, decision-makers are educated and people at the grassroots are urged to speak up and to ask for change from those decision-makers. Much of the

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awareness, education, defining, and pressure are done using the news media. Paid media advertising is occasionally a part of this process, but usually advocates do not have sufficient funds for a paid advertising campaign. The tools of the media advocate are often called "earned media" and include news releases, news events, editorial board meetings, op-eds, letters to the editor, and ongoing relationships with members of the news media.

Before any contacts are made with the media, policy and media advocates need a plan to identify the issue to be addressed and the policy change to be promoted by the media advocacy campaign. The plan must include "damage control" strategies; advocates need to know in advance how to respond to challenges to both their messages and their credibility. For each likely argument, the media advocate should have counter-messages developed, with a strategy for either preempting those arguments or countering them promptly when they occur. In the same vein, they look for cracks in their opponents' credibility and are ready to use those if needed.

The solutions that media advocates seek are always policy solutions. Media advocacy builds support for policy change that is known or thought likely to be effective. This is because media advocacy, like any policy advocacy strategy, is based on the fundamental belief that creating meaningful public health policy creates changes in health related norms, and is the best way to ultimately change key health related behaviors that are major risk factors for preventable morbidity and/or mortality in a population. There are many examples of this, including seatbelt laws, drinking-and-driving laws, and smoking restrictions. All of these policy changes have been shown to alter long-term behavior in ways that would be impossible to do if relying on public health programs and public service announcements alone. Policy change often increases demand for programs and services as well, at least in the short term, as the change becomes normative—such as increased demand for infant car seat classes following a law requiring their use.

Media Advocacy and Health Care Policy

Since health care is a hot topic today among state and national leaders, I see many opportunities for media advocacy as a tool for patient advocates. Media advocacy in health care systems media (e.g., health care and health insurance newsletters) and mass media can be a voice for changing policies, both private and public, that impact the lives of patients and the practice of medicine. Once an "inside strategy" —an internal request for policy to be changed in order to improve patients' health outcomes or experiences with providers — has failed, it may be time to introduce an "outside strategy" such as media advocacy through the public media. In one example from Alabama, Max Michael, a Birmingham physician, wrote an op-ed titled, "For Alabama's most vulnerable, health care is a luxury."[7] This piece was printed in at least 12 newspapers across the state and led to a larger number of television and radio news interviews concerning the need for policy change to expand access to the state's health care system. His media advocacy work helped to personalize the plight of the uninsured in Alabama.

In 1989, when North Carolina had the highest rate of infant mortality in the nation, *The Charlotte Observer* ran an in-depth series highlighting the problem titled "From cradle to grave."[8] In the series of articles and opinion pieces, the newspaper highlighted the many unaddressed gaps in access to prenatal care for poor women in North Carolina. The progressiveness of the state's economic development was in stark contrast to the level of preventive health care available to low income families—including expectant mothers. The public outpouring that followed the news coverage and opinion pieces, combined with the statewide shame of being seen as "the worst of the worst," led to an unprecedented increase in attention to and funding for prenatal care and healthy birth issues. According to the Healthy Start Foundation, a public-private partnership created during the resultant program development, the infant mortality rate in North Carolina decreased 33% between 1988 and 2007.[9]

Today, leaders in North Carolina and the nation are calling for health care reform. Health care providers and other patient advocates can use a combination of personal stories and other framing techniques to bring positive policy change to health care systems. Training health care providers and public health professionals to understand and practice media advocacy would serve the people and the public health of North Carolina well. For example, in a recent news interview Dr. William L. Roper, CEO for the UNC Health Care System and dean of the UNC Chapel Hill School of Medicine effectively used a personal anecdote to frame how electronic medical records might benefit patients by way of improved customer service.[10]

The nation's tobacco control movement has modeled the link between media and policy advocacy over the years. The US Centers for Disease Control and Prevention recommends well-funded, comprehensive tobacco control programs, which include sustained paid and earned media campaigns and development of evidence-based tobacco control policies, such as smoking restrictions and higher cigarette taxes.[11] These recommendations come from evaluations of successful states. California was the first state to implement a comprehensive, statewide tobacco control program, including strong tobacco control media and public policies, which resulted in an adult smoking rate of 14.3% compared to a 22.9% rate in North Carolina.[12] Further, California was the only state in the country in a 2008 Annual Report on Cancer to show declines in both lung cancer incidence and deaths in women.[13]

It's All About the Frame

Once the policy goal takes shape, there is strategy planning that goes back and forth between policy advocates and media advocates working to bring support to the policy solution(s), Lawrence Wallack and his coauthors define steps for successful media advocacy, including 1) framing the issue to get better access to the media and 2) framing the issue for content.[3] This two-step process allows for a systematic way for advocates to plan media advocacy tactics. The media advocate can make decisions about how media exposure can help the cause by answering specific questions, such as: can the issue be introduced to the public as a critical and solvable problem? How can the policy change being sought be presented to the public as the best possible way for the community to address the problem? Can the people in a position to affect change be reached through the news media? Will that best happen on the editorial or opinion page, with news coverage, or in some other way?

Once these kinds of questions are answered, the advocate can begin shaping the story to be presented to the community through the news media. According to Wallack, to draw the media's attention, the story must contain one or more of the acknowledged elements of newsworthiness. For example, in tobacco control, there is often built-in irony and controversy that create a foundation for a news story—especially when combined with a policy initiative. Contacting the news media with a story already infused with newsworthy elements is "framing for access." Here, Wallack is referring to access to the headlines or airwaves—and access to the audience that consumes the news.[3] You can have the best idea ever to address a health issue, but if you don't have access to the community via the news or some other channel, your idea probably won't go anywhere.

Once a reporter is interested in doing a story, the framing effort shifts from "framing for access" to "framing for content."[3] At this point, the advocate is working closely with policy experts on the one hand and on the other closely with the reporter, helping to develop elements of the story that support the policy change being promoted. This might mean coming up with ideas for compelling visuals or finding someone with a personal story to share, making the policy change being promoted seem even more important and thus more likely to succeed.

Enticing a reporter to become interested in a story takes a combination of art, skill, and luck. *The Charlotte Observer* series on teen tobacco use is one example. A media advocate worked with a general assignment reporter on a story in preparation for an anticipated bill in the legislature addressing tobacco sales to minors. The background interview turned into a series of meetings during which facts, documents, and names of other sources were shared with a reporter who became excited about turning a one-day assignment into a series of articles. Asked months later what made her decide to pursue a series rather than a brief news article, the reporter mentioned a "man-bites-dog" moment, when the media advocate told the reporter that mountain area health educators reported smokeless tobacco use among very young boys, as young as two or three, and the use of snuff to ease the pain of teething infants. The reporter wanted to talk to these sources and share with the public these shocking practices; the result was the teen tobacco series.

There is, however, a possible danger to using unusual stories and personal experiences, such as the use of snuff on the gums of teething infants. Every media advocate must be aware of how a personal experience can become a "blame-the-victim" story in the hands of a reporter merely looking for a sensational story. When a personal experience becomes the center of a news story, the article can become framed to allow readers to believe the person "deserves" the health problem because of poor health behaviors, such as lung cancer patients who are smokers. The key is to draw back the frame: include the community's responsibility to prevent the health problem and redirect the blame where it belongs. In this case, the blame fell squarely on the community norm for the use of a product that, when used as directed, results in cancer and other deadly diseases. Through this device, the responsibility can be placed directly on the community and its need to develop norms that support healthier behaviors.

In the hands of a skilled media advocate, with a clear focus on a sound policy outcome, a seemingly random fight for column inches among health advocates can become a strategic set of activities, calculated to result in private and public policy changes to support healthier behaviors and healthy social norms for North Carolina communities. **NCMJ**

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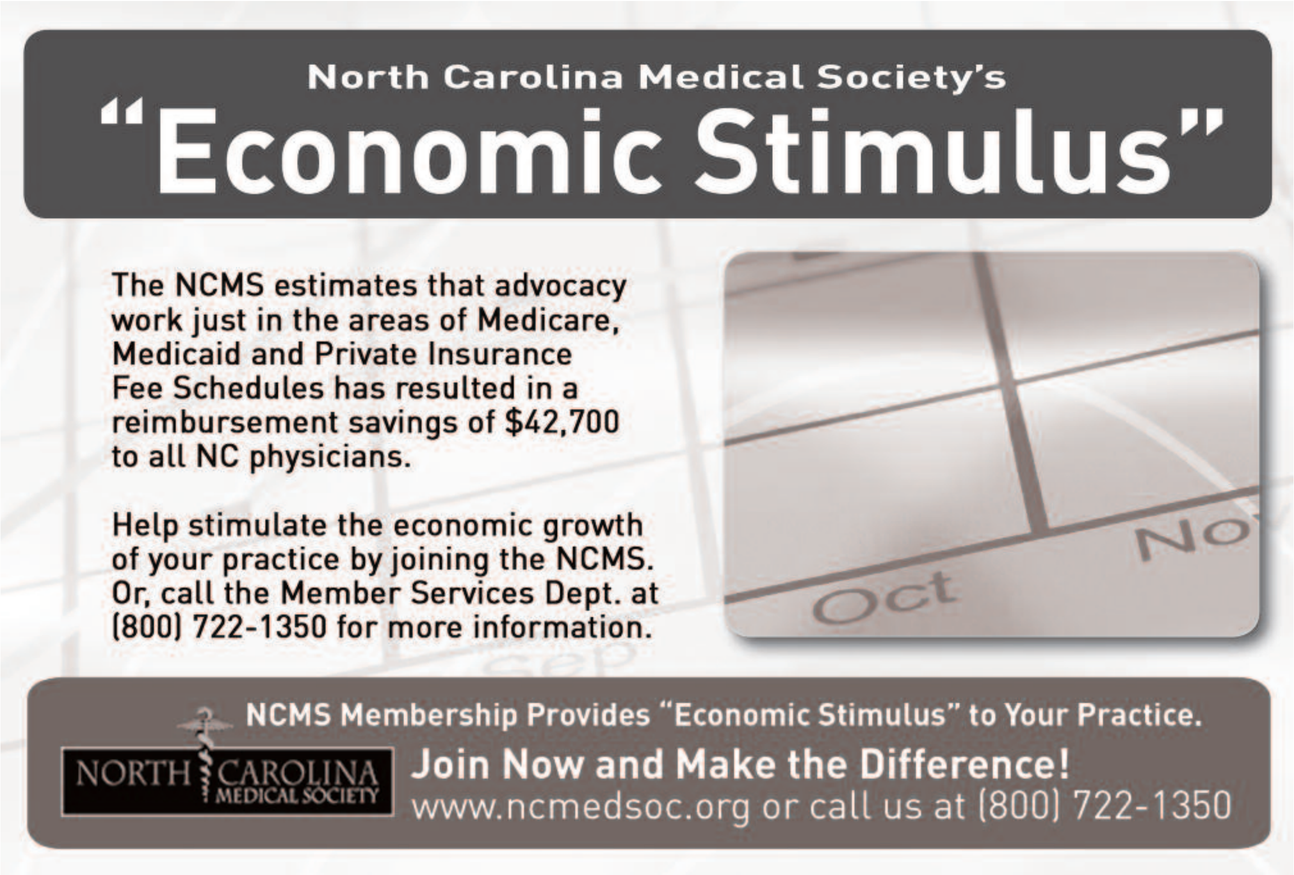

Finding Your Voice as a Patient Advocate:
A Bed's Eye View

Tiffany Christensen

My mother was pressing her back against the wall with such force it looked as though she was attempting to be invisible. Perhaps she was. This was the day I told my doctor that his insensitive comments were so hurtful I no longer wanted him as my physician. I handed him Bill Moyers's book, *Healing and the Mind*,[1] and wished him luck. I was only a teenager when I fired my first doctor, but this was my job; I was training to be my own patient advocate.

As a life-long patient, born with cystic fibrosis and having received two double lung transplants, I know all too well what can happen if I let my guard down in a health care setting. Does the IV bag hanging above my bed have my name on it or is it for Bob down the hall? If I'm being told I need invasive treatment, how can I know that is my best option? When I have three specialists, and they are offering me three different solutions, whose recommendation do I follow? Perhaps the greatest irony of illness is that, in today's complicated health care system, when a patient is at their worst is exactly when they need to be at their best.

Over the years, I have learned that being hospitalized is not a time to relax and heal but rather when I must assume responsibility for steering my own health care ship. If I am too sick to stand at the helm, I must have a friend or family member take over for me. I know now that it is my job to be knowledgeable about my disease process, remain aware of what is being done to and around me, and to find the strength to assert boundaries when my physical or emotional well-being is in jeopardy. In a country where between 44,000 and 98,000 people die each year from medical error,[2] being an informed and alert advocate is not a choice but a necessity.

Medical Advocacy

In most ways, no one will ever know my body better than me. After all, we have been together from the start. I know how my body reacts to medications, what each pain and wheeze indicates, and what treatments have worked best for me in the past. While this is all true, it does not change the fact that, even after all these years, when the team of doctors walk into my exam room I become a deer in the headlights. I stutter, I stumble, and my mind goes blank.

One important part to being a medical advocate is thinking ahead. For example, bring a list of your medications and your questions to every appointment and admission. During your time with the doctor make notes about any changes, suggestions, or regimens you discuss. You may think you will remember it later, but chances are you will have forgotten by the time you reach your car.

If you find yourself in a situation where you or someone you love feels overwhelmed by medical jargon, rushed into making a health care decision, or is uncomfortable with the decisions being made try the three steps listed below and use them as an anchor.

> ***"Perhaps the greatest irony of illness is that, in today's complicated health care system, when a patient is at their worst is exactly when they need to be at their best."***

1. ***Slow down the conversation.*** Simply saying something like "I'm sorry, I'm feeling overwhelmed. Can I take a moment?" can give you the space you need to absorb the information at hand and help you reestablish control.
2. ***State your concerns and ask for clarity.*** Some examples of this may be, "I'm sorry, this isn't making sense to me. Can you go back and tell me why you want to do this?" or "This idea makes me uncomfortable. I am concerned

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that this solution will make things worse, not better." Make sure you voice your opinions, cite relevant past experience and, most importantly, make the professional's recommendation into a dialogue, not a decree.

3. ***Propose your solution.*** Sometimes a patient advocate may have a way of approaching a problem that the professional has never considered. You should propose a solution that makes sense to you. For example, you might say, "I am not ready to move forward with this yet. I need to talk to my other specialists before I make any decisions. I will get back to you after I have talked with them." Another proposed solution may be, "Given what I know about my body, I would like to try the least invasive treatment first. I will give it a month and if that doesn't work, we can revisit the more invasive procedure."

You have the right to be a partner in your own health care. That can be difficult when you are overwhelmed, scared, or feeling ill. Using these three steps, you have a basic guide for being an effective medical advocate. As you develop your own model for being a successful advocate, remember to be a partner in your care and remain a humble, polite, and persistent squeaky wheel.

Emotional Advocacy

Being sick feels like being out of control. As patients, we are being pushed in a wheelchair, moving at a speed and on a route not determined by us. We are waiting for people to bring us food, water, medicine, maybe even oxygen. On a good day it is humbling; on a bad day it is humiliating. While we often think of advocacy as keeping someone safe physically, there is also value in keeping someone safe emotionally.

In my years of waking up in the hospital to bright overhead lights and a team of doctors, residents, and interns surrounding my bed, I have been asked more questions than I care to remember. "How's the pain today?" "Did you go the bathroom?" "Do you still have a fever?" In all of the questions, one aspect remains the same: the inquiries are related to my physical body and never to my emotional health. It is easy to begin to feel like an object, less than human, merely something to be studied. In order to cope with these unpleasant feelings, I have found it is vital to be proactive about my emotional care in the same way I advocate for myself physically.

When I was gravely ill with chronic rejection, I sought out the counsel of a therapist. I have never made a wiser choice in my life. There are so many intense emotions that come with illness: feeling like you have lost your identity, the uncertainty of tomorrow, the deep loss of purpose. I was surprised to find that my family and friends were not the sanctuary for these emotions I once imagined they would be. They love me deeply, but we immediately began to protect each other from our pain; we all worried about burdening the other with heavy emotion. I needed a safe place to go to vent my deepest fears, hurts, and sadness. I believe that without this outlet, I might not be alive today. My emotions were so intense that without the opportunity to give them voice, it is likely the stress would have caused a faster physical decline.

Being an emotional advocate might mean being the "safe person" for someone experiencing a health crisis. It might be the patient herself setting boundaries with those activities or individuals which cause them undue stress. It could be as simple as creating a visiting schedule to avoid the exhaustion that can come from having too many visitors when you are trying to recover. Emotional advocacy goes hand in hand with medical advocacy; I have found it nearly impossible for one to succeed without the other. Being sick feels like being out of control, but there is always the chance to heal, grow, and become stronger emotionally, regardless of the physical outcome.

Systematic Obstacles to Effective Advocacy

In the 35 years I have been a patient, I have witnessed a shift in our health care culture toward patient advocacy. There was a time when my opinions were considered more "cute" than valuable. Today, in many ways, I am a partner in my health care and my perspective is respected. Individual health care professionals are taking up the cause of patient advocacy. Entire health care systems are investigating ways to provide more patient-centered care, examining pro-active options such as apologizing for mistakes, improving patient/professional communication, and designing a real Patients' Bill of Rights. All of this is certainly moving us into an age of patient empowerment, where patient advocacy is accepted and part of the norm.

The benefits of this shift can be seen in favor of both the professional and the patient. When patients participate in shared decision-making with their caregivers, they are more likely to comply with recommended treatment.[3] Health outcomes improve, costs decrease, and patient satisfaction increases.[4,5]

For all of the changes, benefits, and positive results that come from allowing patients to be more proactive in their care, I find there are still mixed messages about "who is boss." For any advocate, there exists an area of the health care system that is largely undefined and worthy of caution. If a patient chooses to advocate for herself and not follow the direction of her physician, she may find herself being written up as going "against medical advice" (AMA). While anyone can understand the need for doctors and health centers to protect themselves against unwise patient choices or poor outcomes, going AMA can carry with it serious ramifications. For example, if I were to go AMA during a time in which I was waiting for a lung transplant, I would risk being taken off the list at my home transplant center. Patients being discharged AMA are also at risk for insurance companies refusing to pay the hospital expenses incurred before going AMA.

Less dramatic than AMA is the ever-threatening "non-compliance" label, which can hold consequences similar to going AMA and can, at the very least, make future health care professionals see you through the lens of "difficult patient." What makes these labels all the more ominous is the lack of a clear understanding as to what constitutes compliance; guidelines outlining what qualifies a patient for one of these labels simply do not exist. When a patient is given such a label, it is by the arbitrary hand that happens to be writing in the chart or filling out the paperwork.

We are taught that patients have the "right to refuse." But is that true? With labels like non-compliant and AMA looming over our heads, how honest is it to say we have that right? Can a patient trust herself to advocate in a system which arbitrarily deems them out of line and unable to make the right decision? Until the terms non-compliant and AMA become clearly defined, patient advocates will continue to walk a dangerous and invisible line. It is essential, as we move into this new health care paradigm, that we find ways to formalize the role and power of patient advocacy for patients, health care students, and professionals.

Opportunities of Illness

Being a patient advocate means something different for everyone. At the heart of advocacy, however, you may find great lessons in trust, compassion, and self-discovery. Through my illness journey I have learned to trust myself as an advocate, worthy of a voice even in a room of medical experts with impressive degrees. As a person who has lived with a debilitating illness, I know what it is to be seen as "less than" because I am not living up to society's expectations. By emotionally advocating on my own behalf, I have been able to experience the peace and joy that comes when we strip away our identity and discover our true, permanent self. Because I believed in my right to be worthwhile even as a sick person, I have been left with a deep impression of what really matters in life. Today, I am healthy. But I know I am no better today than when I could not get off of my couch. I will carry the lessons of illness with me always and for that I am grateful. **NCMJ**

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Patient Advocacy Resources

David K. Jones; Julia Kraemer Lerche

The following is a list of resources for anyone looking for help navigating the health care system including patients, family members, advocates, providers, and administrators. The organizations that are included offer services that range from advocating on national policy issues, to providing direct services to individuals in North Carolina, to improving communication within specific hospitals. This list is not exhaustive and is meant to provide examples of the types of resources available; if you are looking for specific help you may find that these organizations can refer you on to a more appropriate organization. Information presented here was obtained from each organization's website as well as through communications with organization representatives.

Consumers Advancing Patient Safety

Consumers Advancing Patient Safety (CAPS) is a national nonprofit organization focused on improving patient safety. Their website includes resources on how to improve communication between patients and providers.

http://www.patientsafety.org

Duke Health System Patient Advocacy Council and Volunteer Program

Duke's Patient Advocacy Council is made up of volunteers who meet regularly with hospital leadership with the goal of incorporating the patient's perspective in decision-making. The volunteer program consists of more than 250 undergraduate students at Duke University who each commit 40 hours per semester tending to patients' non-medical needs. These include reading to patients, bringing blankets, making sure meals are brought on time, and providing information about hospital and community services.

http://www.dukehealth.org

El Pueblo

El Pueblo is a nonprofit organization focusing on the Latino community in North Carolina through advocacy, public policy activities, and a number of programs. Líderes de Salud, El Pueblo's lay health advisor program, is funded by the John Rex Endowment, and trains advisors to help improve the health and well-being of Latino children and families. Health advisors provide information related to immunizations, dental care, asthma, diabetes, and obesity to Latino families and also support health fairs that link Latino families to local health care resources.

http://www.elpueblo.org

Exceptional Children's Assistance Center

The Exceptional Children's Assistance Center (ECAC) describes itself as "one of the oldest federally funded parent training and information centers in the world." Since 1983, ECAC has functioned as a parent-run resource for other parents, particularly parents of children with developmental disabilities. Their website contains information on how to receive training packets on up to 40 subjects, including attention deficit disorder, autism, and transition to adulthood. For more information on the ECAC and the work of their executive director, see page 92.

http://www.ecac-parentcenter.org/

Inclusive Health: North Carolina Health Insurance Risk Pool

Created by the North Carolina General Assembly in 2007, the North Carolina Health Insurance Risk Pool (NCHIRP) provides access to health insurance for individuals with pre-existing medical conditions who face exceptionally high premiums in the individual insurance market and who do not have access to employer-sponsored health insurance. The health plan also provides resources to help individuals manage their own health.

http://www.inclusivehealth.org

Families USA

Families USA is a policy advocacy organization that describes themselves as the voice for health care consumers. Their website contains information and resources on children's health, Medicaid, Medicare, prescription drugs, the uninsured, and minority health. A section entitled "Resources for Consumers" provides information on obtaining coverage after losing a job as well as contact information for consumer assistance programs.

http://www.familiesusa.org

Family Support Network of North Carolina

The Family Support Network of North Carolina helps families with children who have special needs receive one-on-one support from people who have lived through similar experiences. Their website allows users to search for resources and programs available in each county of the state.

http://www.fsnnc.org

Financial Assistance

A number of organizations provide financial assistance to help patients with insurance premiums, deductibles, and copays. These include:

Caring Voice Coalition:
http://www.caringvoice.org

HealthWell Foundation:
http://www.healthwellfoundation.org

Patient Access Network Foundation:
http://www.patientaccessnetwork.org

Patient Advocacy Foundation Co-Pay Relief:
http://www.copays.org

Patient Services Incorporated:
http://www.uneedpsi.org

Institute for Family-Centered Care

The Institute for Family-Centered Care describes their mission as "promoting the understanding and practice of patient- and family-centered care." This is done through on-site consulting to hospitals, health systems, and other health care organizations. The Institute has worked with more than 150 hospitals from across the United States and Canada. This includes working with branches of the United States Armed Forces to make military medicine family-centered.

http://www.familycenteredcare.org

Legislators

North Carolinians may contact their Members of Congress or Members of the North Carolina General Assembly for help on a variety of issues such as eligibility for veteran health care, Medicare enrollment, or regulation of health care providers.

Senator Richard Burr: http://burr.senate.gov

Senator Kay Hagan: http://hagan.senate.gov

US House of Representatives: To identify your US Representative, go to http://www.house.gov

NC General Assembly: To identify your state Senator and Representative, go to http://www.ncleg.net

North Carolina Center for Hospital Quality and Patient Safety

The North Carolina Center for Hospital Quality and Patient Safety was created by the North Carolina Hospital Association and seeks to improve quality and patient safety through educational, collaborative, and performance measurement programs and services.

http://www.ncqualitycenter.org

North Carolina Department of Insurance

The North Carolina Department of Insurance (NCDOI) provides support for consumers dealing with insurance companies, including the purchasing of insurance and appeals of decisions by insurance companies. NCDOI's Healthcare Review Program contracts with independent review organizations which provide external reviews of insurance company decisions to not cover certain services based on medical necessity. NCDOI also provides Medicare beneficiaries and their caregivers with counseling about Medicare insurance products (Medicare supplement, Medicare Advantage, Medicare prescription drug, and long-term care insurance plans) through their Senior Health Information Program.

Consumer services:
http://www.ncdoi.com/Consumer/consumer_health.asp

Healthcare Review Program:
http://www.ncdoi.com/ER/ConsumerInfo/er_faq.asp

Senior Health Information Program:
http://www.ncdoi.com/Consumer/Shiip/Shiip.asp

North Carolina Department of Justice

The Managed Care Patient Assistance Program managed by the North Carolina Department of Justice provides support for North Carolinians with questions about insurance coverage, access to services, and covered benefits, as well as assistance throughout the insurance appeals process. The Attorney General's office also provides pathways to help for problems with marketing practices and fraud and problems with Medicaid.

http://www.ncdoj.com/law_enforcement/cle_miu.jsp
http://www.nchealthconsumer.org

North Carolina Family Health Resource Line

The North Carolina Family Health Resource Line provides information, referral, and advocacy services to North Carolina's pregnant women and families. The Resource Line provides bilingual assistance for issues related to pregnancy (including substance abuse during pregnancy), child health, family planning, parenting, and child care. The Resource Line also provides information to families about free or low-cost health insurance options for children, including Medicaid and NC Health Choice.

http://www.nchealthystart.org/ncfhrl/index.htm

NC Health Info

NC Health Info is a searchable web portal with information on health-related services in each of the state's 100 counties. In addition to identifying resources related to specific diseases, the web portal provides links to information relating to health insurance, medication, management of health information, and healthy living.

http://www.nchealthinfo.org

North Carolina Justice Center: NC Health Access Coalition

The NC Health Access Coalition advocates for statewide and federal policies affecting health care which "put people first." This includes using litigation, policy analysis, community education, and communication with state leaders.

http://www.ncjustice.org

Parent to Parent USA

Parent to Parent is designed to provide both informational and emotional support to parents of children with special needs. Newly-referred parents are matched in one-on-one relationships with parents who have faced similar situations.

http://www.p2pusa.org

Patient Advocate Foundation

The Patient Advocate Foundation consists of two sister organizations with one devoted to legislative advocacy in Washington, DC, and the other devoted to working with patients. (For more information, see page 169.)

Policy advocacy: http://www.npaf.org

Patient advocacy: http://www.patientadvocate.org

PULSE

PULSE is a nonprofit organization focusing on patient safety. PULSE connects people with patient advocates who check medications, verify medical procedures, help organize instructions, and assist with decision-making. Their website also contains a collection of stories from other people's experiences in which greater patient advocacy was needed.

http://www.pulseamerica.org

Sick Girl Speaks Inc.

Sick Girl Speaks Inc. is the work of Tiffany Christensen, a young woman diagnosed with cystic fibrosis shortly after birth. After her second lung transplant, Ms. Christensen wrote a book intended to help others navigate "the medical maze." She regularly gives workshops designed to educate leaders in health care about the patient's perspective. She also provides workshops, talks, and private coaching for people with chronic illness and their families. (See Ms. Christensen's commentary in this issue of the *Journal* on page 179.)

http://www.sickgirlspeaks.com

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North Carolina Community AIDS Fund

PHILANTHROPY PROFILE

Beth Stringfield; Frank Lombard, MSW, LCSW

Although the number of new HIV cases in the United States has declined since its peak in the 1980s,[1] we are still faced with an increasing number of people living with HIV.[2] An estimated 21% of those living with HIV do not know they are positive,[3] and there is a shift in the populations being infected.[1] In North Carolina, the rate of HIV infections has been increasing since 2000 with approximately 2,000 new infections annually and 32,583 people living with HIV in the state as of 2007.[4] In North Carolina, as is true across the country, it is racial minorities that are disproportionately impacted by this disease, representing 71% of those diagnosed with HIV in 2007, with the highest rate of infections among black males.[4] However, it is black females that experience the greatest disparity with a rate of infection 16 times higher than white women.[4]

North Carolina reflects the southeastern United States in new infections, where the HIV epidemic seems to be hitting the hardest. According to 2001 and 2006 Centers for Disease Control and Prevention Surveillance Reports, while the US has seen new infections decrease, the South's infection rate has increased 2% with the rural southeastern states seeing a 36% increase.[5] The rate of HIV infection in North Carolina is 40% higher than the national rate.[5]

North Carolina is also faced with additional unique barriers to HIV prevention and care. Twenty-five percent of our HIV cases are in rural areas,[5] creating significant difficulties accessing medical care. Public school heath education teaches an abstinence-based curriculum limiting access for students to comprehensive sex education and prohibiting the distribution of contraceptives, including condoms, on school properties.[a] In 2006-2007 the rates of uninsured for nonwhites in North Carolina exceeded the national average, in the case of Latinos by 20%.[6]

We know HIV transmission is the result of behavioral factors, many of which are highly stigmatized behaviors related to sexual activity or substance use. But we also know that poverty, trauma, inadequate access to health care, and economic disparities are engines which drive the dramatic health disparities we see in regard to HIV.

It was against this backdrop that a group of funders began discussions in early 2008 to change the response to HIV in North Carolina. While our state benefits from a multitude of medical and research institutions, many great AIDS service providers, and strong state leadership from our Department of Health and Human Services, our response the HIV epidemic has left much of our population behind in terms of access to HIV prevention and care. A new approach was needed.

By the fall, five funders had come together to create the North Carolina Community AIDS Fund (NC CAF). Blue Cross and Blue Shield of North Carolina Foundation, Kate B. Reynolds Charitable Trust, National AIDS Fund, North Carolina Health and Wellness Trust Fund, and The Duke Endowment all committed funds while the Center for Health Policy at Duke University was chosen as the convener.

The goal of this collaborative is to increase the capacity of communities across the state to respond to the HIV epidemic by funding creative approaches to prevention and care, working with nontraditional partners to bring HIV prevention messages to all populations within the state, working to target rural areas across North Carolina, and working with the agencies providing these services to strengthen their programs and operations so they can do their work better.

North Carolina, with our unique HIV epidemic, needs to find creative solutions that work with our populations, geography, and institutions. Equally, while there has been strong leadership on HIV issues in the state, that leadership has been concentrated, with minimal independent voices advocating for increased HIV services on a state and national level. With this in mind, the North Carolina Community AIDS Fund has three program areas that will help us address these challenges: grantmaking, technical assistance, and AmeriCorps.

Five agencies across the state have received grants for these programs: Chatham Social Health Council, Metropolitan Community Health Services, Student Action with Farmworkers, Western North Carolina AIDS Project, and Women's Center of Wake County. The populations these projects reach out to include: African Americans; people who are lesbian, gay,

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[a] North Carolina GS 115C-81 Basic Education Program.

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Frank Lombard, MSW, LCSW, is the associate director of the Center for Health Policy and Health Inequalities Progam at Duke University.

bisexual, or transgender; Latino youth; African American women; migrant farm workers; and sex workers. These populations are often hardest to reach and in greatest need of HIV prevention education. NC CAF aims to work with these funded projects to develop replicable models and tools that work in our state and which can be shared with others interested in doing similar work.

NC CAF recognizes that it's not only important to have strong programs in the community; the agencies providing those programs must also be strong. The North Carolina Community AIDS Fund will coordinate technical assistance for agencies providing HIV prevention and care services to improve their program development and evaluation—seeking to always increase the level of services provided to the community, as well as organizational capacity building to strengthen the organizations' boards, fundraising ability, networking, accounting procedures, and oversight. We believe that healthier organizations can both focus more attention on their programs and bring more resources into the state to serve our residents.

Finally, the National AIDS Fund AmeriCorps Caring Counts Program will be coming to the greater Triangle area in fall 2009. A team of five people seeking to make an impact in the HIV epidemic will dedicate 11 months to serving our community. These members will increase the capacity of the agencies in which they work but also contribute to the whole community through weekly community service.

NC CAF sees a great need to not only increase the quality of services provided and the capability of those service providers, but understands that true systemic improvements cannot happen without advocacy. Throughout the HIV epidemic in North Carolina, much of the vision around prevention and care has been provided by the Communicable Disease Branch (formerly the HIV/STD Prevention and Care Branch) and the AIDS Care Unit. Led by Evelyn Foust, this relatively small number of dedicated and hard working individuals has often been forced to shoulder the burden of developing and spreading HIV messages across each of the diverse regions of the state and throughout the country. North Carolina has not been as successful at sustaining a community-level advocacy movement to act as a counterbalance to the efforts of our state level policymakers. There are many reasons that this community-level response has been slow to develop and difficult to sustain. The continuing stigma of HIV in North Carolina continues to make disclosure difficult. HIV care providers are overstretched and underresourced in comparison to the needs their clients face. The majority of HIV funding in North Carolina is funneled through the state, creating some hesitation for the community dependent on that funding to invest too heavily in advocacy-related activities. The shift of the HIV epidemic into the most marginalized and disenfranchised populations in North Carolina has created a patient population which in many ways is less equipped towards advocacy than was the largely gay white male cadre of AIDS activists in the 1980s and early 1990s.

This does not mean that advocacy efforts are hopeless or unworthy of effort. In fact, there is a need to redouble our efforts towards developing community-based capacity to engage in advocacy across the wide continuum of related activities and to involve strong yet diverse collaboratives, both old and new. It requires creative thought and patience as we support those new to advocacy work to become engaged, and as we develop diverse routes through which those who are infected and affected can safely participate. The NC CAF is seeking through its work to support communities in a number of ways, all of which will ultimately lead to an increased capacity of these communities to develop and engage in advocacy-related work.

While North Carolina has developed a strong network to serve those at risk of and living with HIV, we have left behind many of those in greatest need of our services. This collaboration is an opportunity to fill in the gaps in services, to address the needs that are hardest to meet and the populations hardest to reach, to increase the capacity of our service delivery system to both provide better services and to become stronger organizationally, and to expand the leadership roles within our state, turning the tide on the HIV epidemic in North Carolina. **NCMJ**

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Running the Numbers

A Periodic Feature to Inform North Carolina Health Care Professionals about Current Topics in Health Statistics

From the State Center for Health Statistics, North Carolina Department of Health and Human Services
http://www.schs.state.nc.us/SCHS

Hospice in North Carolina

Hospice care is becoming an increasingly important component of overall medical care in the United States and in North Carolina. In providing active care of patients with advanced, progressive, and incurable disease, hospice care:

- Provides relief from pain and other distressing symptoms
- Enhances quality of life when the length of life is limited
- Regards dying as a normal process
- Does not intend to hasten or postpone death
- Incorporates psychological and spiritual aspects of patient care
- Uses a team approach to provide a support system for patients and their families

In most cases, hospice care is provided in the patients' own home. However hospice care can also be provided in freestanding hospice facilities, hospitals, nursing homes, and other long-term care facilities and is available to persons of any age, religion, or race. Members of the hospice team include physicians (usually the patient's own physician), nurses, social workers, counselors, trained volunteers, and other therapists. This team makes regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week for emergencies. Bereavement care and counseling for surviving family and friends is also part of hospice care.

The first hospice program opened in North Carolina in 1979. In early 2009 there are now 76 hospice programs providing hospice care in all 100 counties in the state. The increase in hospice providers is associated with a growing number of persons who die while cared for by hospice. Those persons receiving hospice care at the time of their death has nearly tripled from 9,246 in 1994 to 24,823 in 2007. The percentage of those who die under the care of hospice increased from 14.6% to 32.7% of all North Carolina resident deaths during this period (see Table 1).

Not all deaths in North Carolina are eligible or appropriate for hospice care; sudden death from heart disease or many of the deaths due to injury and violence cannot be accommodated in a hospice setting. Cancer diagnoses accounted for approximately 42% of hospice admissions in 2007. The ratio of cancer to non-cancer admissions has steadily decreased since 1996 when more than 73% of hospice admissions had cancer diagnoses. Hospice programs across the country and in North Carolina now care for more persons with non-cancer diagnoses than those with cancer.

Table 2 (page 188) shows the number and percentage of hospice patients in 2007 by admission diagnosis. Cancer was the leading diagnosis, followed by dementia, and unspecified debility.

Table 1.
Total Deaths of North Carolina Residents and the Number and Percentage Served by Hospice, 1994-2007

Year	Total Deaths	Hospice Patient Deaths	Percentage of Deaths Served by Hospice
1994	63,188	9,246	14.6
1995	64,830	10,040	15.5
1996	66,188	10,796	16.3
1997	65,880	10,913	16.6
1998	67,798	12,140	17.9
1999	69,304	12,546	18.1
2000	71,732	13,420	18.7
2001	70,738	14,590	20.6
2002	71,780	15,723	21.9
2003	73,230	16,889	23.1
2004	72,191	18,725	25.9
2005	74,376	20,927	28.1
2006	74,419	22,653	30.4
2007	75,803	24,823	32.7

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Hospice care is covered by Medicare and Medicaid, and most private insurance plans, HMOs, and other managed care organizations. If a person does not have coverage through Medicare, Medicaid, or a private insurance company, hospices will work with the person and their family to ensure needed services can be provided. In North Carolina in 2007, approximately 84% of patients receiving hospice care had their care paid for by the Medicare Hospice Benefit. Eighty percent of hospice patients in North Carolina in 2007 were age 65 and older, while 20% were less than age 65.

One of the greatest barriers to entering hospice care is the fear of dying. However, what people fear most is reaching the end of life connected to machines, dying in pain, dying alone, and being a burden to family.[1] Lack of knowledge about hospice care and its support services contributes to the lack of use of these services. Few people want to die in a hospital, but many people do die there. Among all 2007 deaths of North Carolina residents, 45% occurred in a hospital and 26% occurred at home. In comparison, 11% of North Carolina hospice deaths occurred in a hospital and 48% occurred at home (see Figure 1).

As North Carolina's population ages rapidly in the coming years, there will be more interest and concern about end-of-life care. Health care professionals and the general public are increasingly choosing hospice care over other forms of health care delivery at the end of life. With one-third of persons who die in North Carolina currently receiving hospice care, end-of-life care and hospice have become a more central component of North Carolina's health care system.

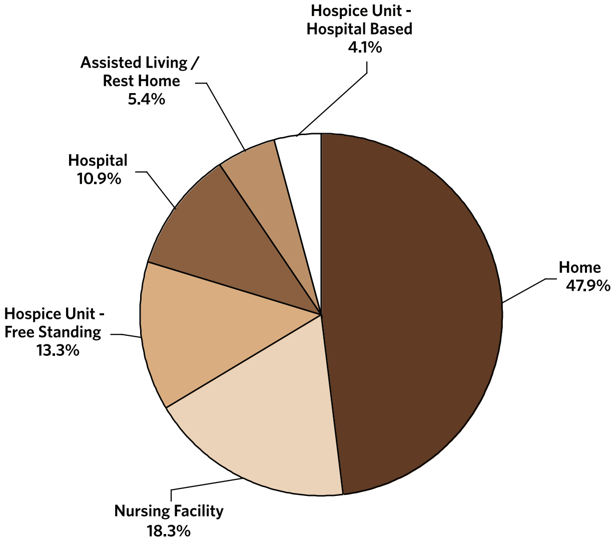
For more information about hospice and related topics go to the website of the Carolinas Center for Hospice and End of Life Care at http://www.carolinasendoflifecare.org.

For hospice statistics, including county-level information, go to http://www.carolinasendoflifecare.org/Statistics2006.html.

Table 2.
North Carolina Hospice Patients Admitted in 2007: Number and Percentage by Admission Diagnosis

Diagnosis	Number of Patients	Percentage of Patients
Cancer	13,002	42.3
Dementia	3,812	12.4
Debility (unspecified)	3,675	12.0
Heart disease	3,566	11.6
Lung disease	2,691	8.8
Stroke	987	3.2
Kidney disease	901	2.9
Other diagnoses	746	2.4
Liver disease	557	1.8
Motor-neuron disease	530	1.7
HIV/AIDS	144	0.5
Amyotrophic lateral sclerosis	135	0.4
Total patients	30,746	100

Figure 1.
North Carolina Hospice Patient Deaths in 2007 by Location



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Spotlight on the Safety Net

A Community Collaboration

Kimberly Alexander-Bratcher, MPH

Improving How the Safety Net Works

Health care safety net organizations are some of the most important health care providers available to the growing numbers of uninsured in the state. When we speak of the safety net we most often are referring to federally qualified health centers, free clinics, public health departments, rural health centers, school-based and school-linked health centers, and hospitals. There are also many other health care practitioners and providers who are striving to meet the needs of the uninsured and underinsured. Most of the formal safety net organizations provide preventive and primary care services. Some offer a wider array of services including chronic disease management, prescription and medical equipment assistance, and enabling services (such as transportation or interpreter services). The wider medical care community also provides services and support. Hospitals provide a broad array of services to the uninsured, but are the most expensive setting so that is not the place where people should ideally be receiving primary and preventive services. Because of the great unmet needs and limited resources, there is also a need to coordinate services to avoid duplication and ensure that the limited safety net resources meet the needs of as many people as possible. This *Spotlight on the Safety Net* features several programs that are intended to help patients and practitioners access care, pay for services, coordinate clinical care, and share information and best practices.

The North Carolina Institute of Medicine's (NCIOM) NC Health Care Help website, www.nchealthcarehelp.org, which connects North Carolinians with free and reduced health care in their communities, lists more than 200 safety net organizations across the state.[1] Each organization is unique in the way it serves the community, but none of them can meet all of the health care needs of the uninsured. In 2003, the NCIOM estimated that only 25% of the uninsured received their primary care services through safety net organizations.[2] Many practitioners and institutions provide free or low cost care to the extent they can.

In 2005, the North Carolina General Assembly created the North Carolina Community Health Center Grants program to expand the availability of safety net services across the state.[3] The program awarded grants to 71 organizations expecting to serve an additional 39,000 uninsured individuals in SFY 2008.[4] Many other well-qualified organizations applied for funds that would have increased access for an additional 60,000 uninsured individuals across the state, however there was insufficient state funds to cover all of the needs.

Recently leaders of safety net organizations, provider associations, and hospitals came together and made a united effort to expand state funding for safety net organizations. This collaboration at the state level required buy-in from the major stakeholders, and is an excellent example of coalition building among provider organizations to support expanded access to care. Ben Money, chief executive officer of the North Carolina Community Health Center Association, said the statewide collaboration, "has fostered a greater cooperation and understanding among the association of safety net providers as to the unique role of each organization in providing care to the uninsured. I feel that this collaboration at the association level is having an effect in developing safety net partnerships at the community level."

"The North Carolina Association of Free Clinics believes strongly in a teamwork approach to tackling the challenges we all face in expanding access to health care for the uninsured. Through our collaborative efforts, we are able to achieve far more than we ever could on our own, help bridge the gap for the uninsured in new and innovative ways, and provide an example for local communities to follow," noted Jason Baisden, executive director of the North Carolina Association of Free Clinics.

The Community Health Center grants helps support the expansion of specific safety net services within particular communities. However, these grants are not used to build coordinated networks of care for the

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uninsured. In 2008, the North Carolina General Assembly began funding HealthNet to support the development of community collaborations for the uninsured. Sixteen communities covering 27 counties received HealthNet funding in its first year. Private foundations, including the Blue Cross Blue Shield of North Carolina Foundation and The Duke Endowment, have also provided funding for this type of collaboration.

Albert J. Osbahr, MD, president of the North Carolina Medical Society and medical director of the Occupational Health Center at Catawba Valley Medical Center in Hickory, North Carolina said, "In these trying economic times, we have many of our fellow citizens who are uninsured and unemployed. With this, there are many more people without appropriate health care coverage. The North Carolina Medical Society is very concerned about access for all our citizens, but especially those that are most vulnerable. Collaboration is essential if we have any chance of meeting the health care needs of this vulnerable population."

That sentiment is at the heart of the creation of the Care Share Health Alliance. The nonprofit provides technical assistance and coordinates grantmaking provided to support safety net providers who care for the uninsured across the state. With representatives of the major health care foundations, state agencies, safety net organizations, health professional organizations, hospitals, and other organizations that support community care to the uninsured, the goal of the Care Share Health Alliance is to help communities strengthen their safety net infrastructure and develop local Collaborative Networks of care.

"Safety net providers in every community across our state are reaching out to the uninsured, often in ways that lack coordination and efficiency. Hospitals certainly want to be involved in those efforts, to see them reach the most vulnerable in our communities, and to achieve greater efficiency in this time of shrinking resources. Having state organizations work closely together sets an example for community caregivers and provides a vehicle for surmounting issues that reach beyond local communities," said Bill Pully, president of the North Carolina Hospital Association.

By working together, safety net providers have been able to expand the array of services and the numbers of uninsured they serve. However, the problems of the uninsured cannot be met solely through safety net expansions. Ultimately, everyone needs a source of coverage to help finance basic health services. Congress and state legislators are currently exploring options to expand coverage to the uninsured. Until that time, North Carolina can help meet the health care needs of the growing numbers of uninsured by supporting and strengthening the safety net.

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Kellan Chapin, executive director of Care Share Health Alliance, and
Pam C. Silberman, DrPH, JD, president and CEO of the North Carolina Institute of Medicine
contributed to this article.

Readers' Forum

To the editor:

The January/February 2009 issue of the *North Carolina Medical Journal* (Vol. 70, No. 1) provided excellent and detailed information regarding substance abuse in North Carolina. Information was presented from the aspect of prevention and recovery, but with only passing remarks about the clinical burden of substance abuse and mental health disorders on the state's emergency departments.

In the 2007 NC DETECT Annual Report of Emergency Department Data (http://ncdetect.org), the disorders of substance abuse/intoxication/withdrawal accounted for 11.2% of statewide ED visits. Psychiatric disorders accounted for 7.7% of ED visits. The two groups of disorders together accounted for an amazing 17.9% of statewide ED visits in North Carolina, greater than ED visits for chest pain/ischemic heart disease (11.9%); diabetes (7.8%); asthma (4.4%); or motor vehicle crashes (2.5%). It is ironic that while there is effort to minimize ED visits and provide improved and cost-effective care for disorders such as diabetes and asthma and primary prevention methods (airbags, seatbelts, etc.) to decrease mortality and morbidity from motor vehicle crashes, no such approach is being used to minimize ED visits for substance abuse or mental health, and no such approach is currently able to provide alternative emergency services other than the closest emergency department.

The Brief Motivational Intervention (BMI, http://www.ed.bmc.org/sbirt/), an adaptation of Substance Abuse Screening and Brief Intervention in Primary Care (SBIRT), is being used in emergency departments in Massachusetts and should be applied to North Carolina emergency departments, although there are time and cost challenges to wide implementation.

So, in summary, emergency physicians and emergency departments also carry the clinical burden of care for those with substance abuse and mental health disorders. A comprehensive system of care needs to recognize the important role of the emergency department and enable it as a location for both prevention and the start of recovery-oriented care. Emergency physicians should participate in policy planning so that the solution is truly comprehensive.

Judith E. Tintinalli, MD, MS
Professor
UNC School of Medicine
April 15, 2009

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