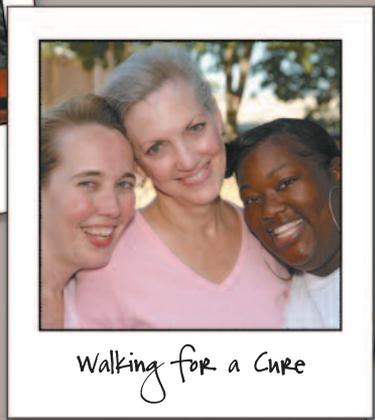
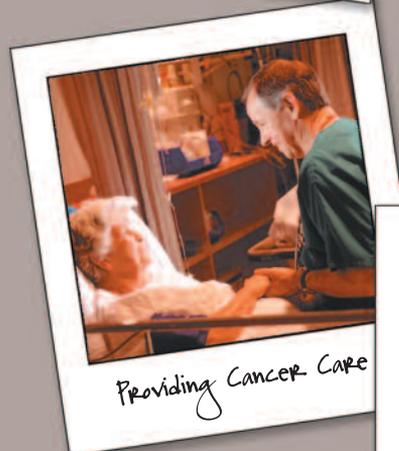
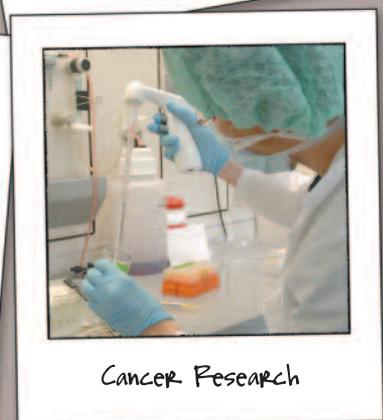
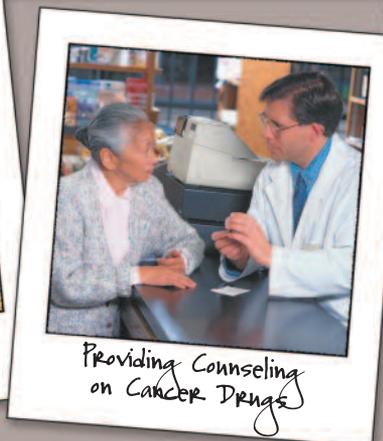
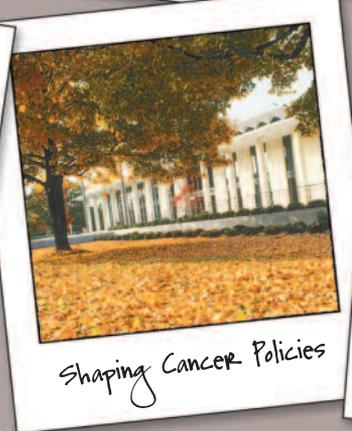
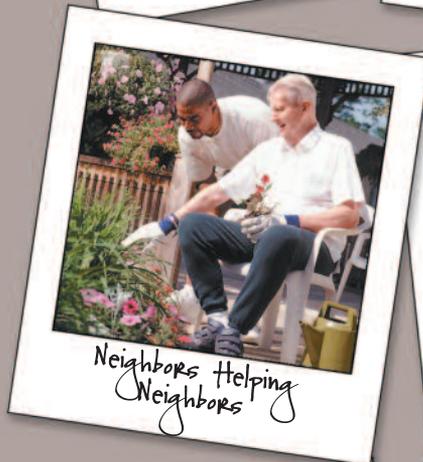
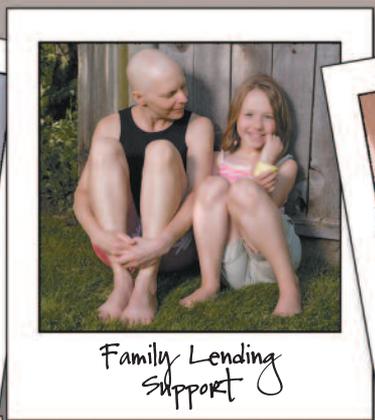
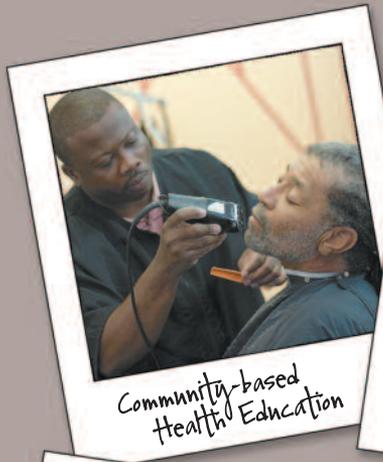


North Carolina MEDICAL JOURNAL

a journal of health policy analysis and debate



Creating a Community to Combat Cancer



Hong Jin Kim, M.D., Julie Blatt, M.D., Richard M. Goldberg, M.D., Lisa A. Carey, M.D., Paul A. Godley, M.D., Ph.D., Paola Gehrig, M.D.

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North Carolina MEDICAL JOURNAL

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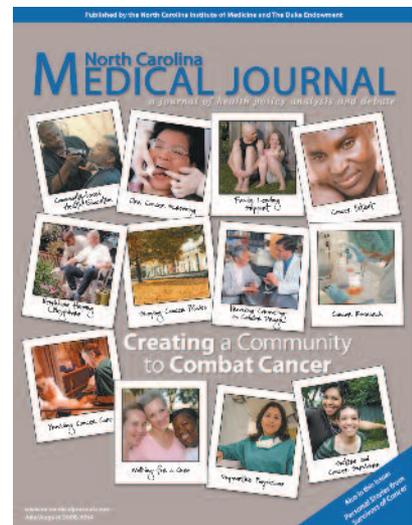
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Tarheel Footprints in Health Care

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

Orren Beaty III, DO, PhD Pediatric Hematologist/Oncologist, Asheville
William R. Berry, MD Hematologist/Oncologist, Raleigh
Gloria D. Frelix, MD, MPH Radiation Oncologist, Greenville

It takes special people to work in cancer. Although literally thousands of compassionate and effective professionals could be profiled, 3 extraordinary physicians are highlighted in this issue's Tarheel Footprints. Dr Orren Beaty, a pediatric oncologist in western North Carolina, provides care to a very special population who often are unable to advocate for themselves—children and adolescents with cancer—and to their families. Dr Bill Berry, a medical oncologist in Raleigh, North Carolina, has the perspective of an oncologist and a cancer survivor and combines both to help his patients. Dr Gloria Frelix, a radiation oncologist in Greenville, North Carolina, serves those who live in one of the most underserved regions of our state and is a champion for those who are most in need.



Dr Orren Beaty spent his formative years in northern Virginia and graduated from the University of Richmond. He then obtained a PhD in physiology at Wake Forest University. He obtained his medical degree from Kirksville College of Osteopathic Medicine, where he held research and faculty appointments both at Kirksville and at the Mayo Clinic. He first came to North Carolina to complete a residency in pediatrics at East Carolina University, followed by postdoctoral research at St. Jude Children's Research Hospital in Memphis, Tennessee. His first rotation during residency at East Carolina was in adult hematology/oncology. He was hooked and from that point on he eagerly awaited that rotation again. Under the tutelage of pediatric oncologists Tate Holbrook and Charles Dasher, his future course was set. Beatty subsequently settled in Asheville, where he has been instrumental in establishing the first pediatric oncology services in western North Carolina. Dr Beatty helps his young patients understand how treatable their disease is. Dr Beatty wants to be there for

his patients and their families and bring them the latest and best information so they can make informed decisions. He also believes in being his patients' number one advocate.



Dr Bill Berry grew up in Mitchell County, in the mountains of North Carolina. Dr Berry's father was a primary care physician who died suddenly when Bill was only 7 years old. Although this was an untimely loss in his life, a family tradition of healing evidently prevailed. After graduating from Davidson College, Berry attended Duke University for medical school and residency training in internal medicine. Dr Berry also completed 2 fellowships in hematology and oncology while at Duke. Bill Berry was impacted by an oncology rotation at Duke. He was immediately drawn to the challenges and many demands associated with cancer care; it was never boring and required him to have intense interaction with patients and families. Dr Berry credits his work ethic and current practice style to Dr Olin Puckett, his premed advisor and biology professor at Davidson, and Dr Harold Silberman at Duke. Berry founded

Cancer Centers of North Carolina and has been instrumental nationally in prostate cancer research and treatment. He is a prostate cancer survivor since 2002 which provides him with a unique perspective as a physician. He has become an active participant in local and statewide prostate cancer support and advocacy activities and willingly shares a clinical knowledge that has been combined with personal experience. Dr Berry indicates he must be up-to-date on the latest treatments and must educate patients with accurate information about treatment and prognosis—whether it is pessimistic or optimistic. He believes in making patients equal partners in the treatment plan.

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a journal of health policy analysis and debate

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ON THE COVER: The photos on the cover of this issue are a representation of the people in the community whose involvement contributes to the successful care of a cancer patient and his or her ultimate survival.

IN THIS ISSUE: Personal stories from the North Carolina Comprehensive Cancer Program, **Faces of Cancer** are scattered throughout this issue of the *Journal*. This campaign is designed to highlight and honor North Carolina cancer survivors. The personal stories are intended to help spread awareness about the varying demographics, ethnicities, and types of cancers that affect North Carolinians. If you or someone you know is a cancer survivor and you would like to share a story to inspire others, please contact the North Carolina Comprehensive Cancer Program at 919.707.5300 or nccompccancer (at) ncmil.net.

Photo credit cover, second row, second photo from left: NC Division of Tourism; photographer Bill Russ

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Dr Gloria Frelix, a native of Columbia, Mississippi, and was 1 of 8 children born in a family that was “poor but didn’t know it.” She had achievement and service instilled in her by parents who insisted that their children get a college education and be of service to others. A graduate of Meharry Medical College, she completed a residency in radiation oncology at George Washington University and a 3-year fellowship at the Albert Einstein School of Medicine. She later obtained a Master of Health Administration from the University of North Carolina, School of Public Health. Frelix joined the faculty at the East Carolina University School of Medicine in 2005 and was recently elected president of the Old North State Medical Society. Gloria Frelix traces her connection to oncology to the loss of a beloved Brownie Scout leader who died from breast cancer. Frelix has committed herself to healing and saving so that cancer will not prematurely claim another life. Dr Frelix tries to treat patients as though they were members of her own family. She has helped bring attention to the special needs of African American women as they cope with breast cancer. She is proactive in helping them understand how treatable the disease is. She wants to spend the rest of her life working as hard as she can to eliminate health care disparities, leaving eastern North Carolina better than she found it.

The *North Carolina Medical Journal* is proud to recognize these 3 compassionate, committed, and skillful cancer specialists, each of whom has made and continues to make a difference in the lives of the people of North Carolina. However, this recognition is not for them alone; it is meant to be shared with all the cancer care providers who make a difference in North Carolina.

*Contributed by Walter L. Shepherd, MA,
director, North Carolina Comprehensive Cancer Program*



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Field Hypotension in Patients Who Arrive at the Hospital Normotensive: A Marker of Severe Injury or Crying Wolf?

Paul J. Schenarts, MD, FACS; Sachin V. Phade, MD; Steven C. Agle, MPH, MD; Claudia E. Goettler, MD; Scott G. Segraves, MD; Mark A. Newell, MD; Michael F. Rotondo, MD

Abstract

Introduction: Trauma patients with hypotension in the field who arrive at a hospital with a normal blood pressure (BP) may not be recognized as significantly injured.

Methods: Over a 5-year period, demographic, injury severity, and disposition data were retrospectively analyzed for patients ≥ 16 years of age with documented hypotension in the field (systolic BP ≤ 90 mmHg) and normal BP (systolic BP > 90 mmHg) on hospital arrival (hypotensive group). This group was compared to patients with normal BP in the field and on hospital arrival (normotensive group).

Results: During the study, 2207 patients with documented BP were transported directly from the scene. Of this number 44 (2%) were assigned to the hypotensive group, 2086 (94%) were assigned to the normotensive group, and 77 (4%) patients were hypotensive on hospital arrival. The hypotensive group had a systolic BP in the field of 70 ± 26 mmHg compared to 140 ± 26 mmHg in the normotensive group ($p < 0.0001$). Arrival BP at the hospital was normal in both groups. Compared to the normotensive group, the hypotensive group had higher Injury Severity Scores (22.0 vs 11.1, $p < 0.0001$), lower Glasgow Coma Scores (10.8 vs 14.0, $p < 0.0001$), lower Revised Trauma Scores (6.5 vs 7.4, $p < 0.001$), more emergency department deaths (7% vs 0%, $p < 0.001$), longer lengths of stay in the intensive care unit (8.6 vs 7.0 days, $p < 0.0001$) and hospital (14.0 vs 7.0 days, $p < 0.0001$), and increased hospital mortality (18% vs 4%, $p < 0.001$).

Limitations: The retrospective design and exclusion of patients without documentation of BP in the field may have resulted in selection bias.

Conclusion: Despite these limitations, field hypotension is a marker of significant injury in patients arriving at the hospital normotensive.

Obtaining a blood pressure (BP) is fundamental in the initial evaluation and management of traumatically injured patients and is frequently one of the few vital signs immediately available on the scene of an accident. However, multiple studies have found that BP obtained in the field may be inaccurate.¹⁻³ The human ear is almost deaf to the sounds

needed to measure BP. The frequency of Korotkoff sounds (25-50 Hz) used in the auscultatory method of BP determination is near the limits of human sound detection (16 Hz).⁴ This situation is further complicated by the out of hospital environment that may inhibit the ability to hear. As a result of this limitation, it is tempting to dismiss the significance of field hypotension in

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patients who arrive at the hospital with a normal BP. In a busy emergency department, a patient with a normal BP at time of hospital arrival is at risk for undertriage and delay in identifying significant injuries. In a hospital with limited resources, a normal arrival BP may also mislead the physician into delaying transfer to a higher level of care when early transfer is appropriate. The purpose of this study was to evaluate the significance of field hypotension in patients who arrived directly from the scene at a rural trauma center with a normal blood pressure. Our hypothesis was that hypotension in the field is a marker of severe injury in patients who arrive at the hospital normotensive.

METHODS

University Health Systems of Eastern North Carolina operates a Level I trauma center which serves 29 counties in eastern North Carolina. This region has a predominately rural landmass of 13 735 square miles and a population of 1.5 million. According to the North Carolina Office of Emergency Medical Services (EMS),^a there are 4203 EMS providers in this region of which 2.4% are certified prehospital providers, 63.3% are basic Emergency Medical Technicians (EMTs), 15.8% are intermittent EMTs, and 18.5% are paramedics (EMT-Ps). There are 69 volunteer EMS agencies and 239 paid EMS agencies of which 50 provide only basic life support with the remainder providing advanced life support.

The trauma registry and performance improvement database of the University Health Systems of Eastern Carolina has been in place for 14 years. Data is obtained and managed as follows: a data collector abstracts raw demographic, vital signs, and injury severity data directly from the written chart and prehospital record at time of admission and hospitalization; concurrent with the patient's hospitalization, complications are identified and recorded in multiple settings including trauma morning report, clinical rounds, scheduled performance improvement meetings, and chart reviews. Using this method, data on all trauma patients admitted to the hospital by the trauma service are entered into the database. All patients evaluated by the trauma service are considered trauma activations. Validation studies on various data points are performed on a monthly basis, and the accuracy of the database is consistently between 98% to 100%.

After obtaining approval from the East Carolina University Institutional Review Board, a retrospective review of our National Trauma Registry of the American College of Surgeons (NTRACS) database from January 1, 2000 through December 31, 2005 was performed. Data were collected and analyzed for all patients aged 16 years or older who had documented field hypotension, defined as systolic BP < 90 mmHg, but arrived normotensive in the ED, defined as an initial systolic BP ≥ 90 mmHg (hypotensive group). Analyzed data included demographic, mechanism of injury, neurologic injury severity as determined by Glasgow Coma Scale⁵ (GCS), anatomic injury severity as

determined by Injury Severity Score⁶ (ISS), altered physiology as determined by Revised Trauma Score⁷ (RTS), emergency department (ED), and hospital discharge disposition information. Patients were assigned to the hypotensive group if they experienced any episodes of hypotension prior to arrival at the hospital. This group was compared to patients who were normotensive both in the field and on arrival to the ED (normotensive group). Methods used to calculate GCS, ISS, and RTS are presented in Table 1. In both the prehospital and hospital settings, BP was obtained using the auscultatory method, an automated oscillometric device, or the palpation method. Due to use of

Table 1.
Injury Severity Scoring Systems

GLASGOW COMA SCORE (GCS)

	Score
Eyes:	
Open spontaneously	4
To verbal command	3
To pain	2
No response	1

Motor Response:

Obeys	6
Localize to pain	5
Withdrawal to pain	4
Decorticate posturing	3
Decerebrate posturing	2
No response	1

Verbal Response:

Oriented	5
Disoriented	4
Inappropriate	3
Incomprehensible	2
No response	1

REVISED TRAUMA SCORE⁷ (RTS)

RTS = (0.7326 x systolic BP) + (0.2908 x respiratory rate) + (0.9368 x GCS)

INJURY SEVERITY SCORE⁶ (ISS)

ISS is an anatomic injury scoring system based on division of the body into 6 separate regions (thorax, abdomen, head/neck, face, bony pelvis/extremities, external structures). Injuries in each area are assigned an abbreviated injury score (AIS) which ranges from 1-6 with 6 being a severe injury. The highest AIS for each of the 3 most severely injured regions are squared and then added together to calculate the final score.

a The North Carolina Office of Emergency Medical Services collects and maintains data which is provided to each trauma center by way of personal communication.

the palpation method, only systolic BP was utilized in this study. Only patients transported directly from the scene with complete data were included in this study; those patients transferred from other hospitals or those with incomplete data were excluded.

Statistical analysis was performed using chi square test, Student's t-test, and ANOVA, with significance set at a value of $p < 0.05$.

RESULTS

Over the 5-year study period, 7199 patients were evaluated in the prehospital setting by EMS personnel and admitted to the hospital by the trauma service. Of this number, 3493 patients were transported directly from the scene. Of these, 2207 had documented BP in the field and on arrival to the ED and were therefore included in the analysis. Forty-four patients were hypotensive in the field and normotensive on arrival in the ED and assigned to the hypotensive group. This group was compared to 2086 patients who were normotensive in both the field and on arrival in the ED (normotensive group).

The following patients were excluded from analysis: 77 patients who were hypotensive on arrival in the ED; 1286 patients transferred directly from the scene whose blood pressure was not documented; and 3706 patients who were transferred from other hospitals.

Neither age nor gender were significantly different between study groups. The mean age of the hypotensive group was 43.3 ± 18 years versus 49.7 ± 24 years in the normotensive group. Males represented 52% of the hypotensive group and 56% of the normotensive group. The mechanism of injury differed between groups with blunt trauma accounting for 84% in the hypotensive group compared to 93% in the normotensive group, a significant difference at $p = 0.02$.

Indicators of injury severity are summarized in Table 2. The mean systolic BP in the field was 70 ± 26 mmHg in the

hypotensive group compared to 140 ± 26 mmHg in the normotensive group. Blood pressure on arrival at the hospital was within normal range in both groups. The mean ISS of the hypotensive group was double that of the normotensive group. Injury severity scores greater than 16 indicate severe injury and those greater than 25 indicate critical injury; both scores were significantly increased in the hypotensive group compared to the normotensive group. The mean Glasgow Coma Scores (GCS) and Revised Trauma Scores (RTS) were significantly lower in the hypotension group compared to the normotensive group.

Data addressing ED disposition, hospital and intensive care unit length of stay (LOS), ventilator days, and hospital discharge disposition is summarized in Table 3. The ED disposition of patients was as follows: 34% of patients in the hypotensive group were admitted directly to the operating room; 27% to the intensive care unit; and 7% died in the ED. Only 18% of patients in the normotensive group went directly to the operating room from the ED, and 13% admitted directly to the intensive care unit. No patients in this group died in the ED. The intensive care unit LOS and hospital LOS were significantly longer in the hypotensive group compared to the normotensive group.

Disposition at hospital discharge was also significantly different between groups. Fifty-five percent of the hypotensive group returned home, 14% required inpatient rehabilitation, 5% required placement in a skilled nursing facility, and 18% died. In the normotensive group, 59% returned home, 17% required rehabilitation, 10% required a skilled nursing facility, and 4% died. The mortality for patients admitted to the hospital was significantly different between groups: 18% of patients in the hypotensive group died whereas only 4% of the normotensive group died after hospital admission.

Table 2.
Injury Severity Data

Parameter	Normotensive Group	Hypotensive Group	p-value
Mechanism	93% blunt	84% blunt	0.02
Systolic BP Scene	140 ± 26 mmHg	70 ± 26 mmHg	< 0.0001
Systolic BP Hospital	142 ± 26 mmHg	125 ± 22 mmHg	< 0.0001
Blood Transfusion	0.4 ± 1.7 units	2.4 ± 3.5 units	< 0.0001
Injury Severity Score	11.1 ± 9.5	22.0 ± 17.9	< 0.0001
Injury Severity Score (>16)	23% (480)	57% (25)	< 0.001
Injury Severity Score (>25)	11% (229)	30% (13)	< 0.0001
Glasgow Coma Score	14.0 ± 3.2	10.8 ± 5.6	< 0.0001
Revised Trauma Score	7.4 ± 1.3	6.5 ± 2.0	< 0.001

Data presented as mean \pm standard deviation or percent (patients)

Table 3.
Disposition and Length of Stay Data

Parameter	Normotensive Group	Hypotensive Group	p-value
ED disposition			
OR	18% (376)	34% (15)	
ICU	13% (271)	27% (12)	<0.01
Death	0%	7% (3)	
ICU LOS	7.0 ± 10.3 days	8.6 ± 7.5 days	<0.0001
Ventilator days	7.8 ± 12.7 days	8.8 ± 9.9 days	<0.001
Hospital LOS	7.0 ± 9.7 days	14.0 ± 21.7 days	<0.0001
Hospital disposition			
Home	65% (1356)	61% (25)	
Rehab	19% (397)	14% (6)	
SNF	12% (250)	7% (3)	<0.001
Death	4% (83)	18% (7)	

ED emergency department; OR operating room; ICU intensive care unit; LOS length of stay; SNF skilled nursing facility
Data presented as mean ± standard deviation or percent (patients)

DISCUSSION

Determination of an accurate blood pressure is fundamental to the initial triage and evaluation of traumatically injured patients. Despite the importance of this measurement, determination of BP in a field environment may be difficult and inaccurate.²⁻⁴ These inaccuracies may be the result of ambient noise, motion artifact, weak pulses, and faulty equipment.^{2,4,8,9} A rural environment may further contribute to these difficulties as many EMS agencies are volunteer-based, and members may lack frequent experience with severely injured patients. Patients in rural settings also have prolonged discovery and transport times, are at greater risk for deterioration prior to evaluation at a trauma center, and have increased mortality.¹⁰ Given these findings it is important that reports of hypotension in the field not be dismissed in those patients who arrive with a normal BP.

In this study hypotension was defined as a systolic BP of less than 90 mmHg and normotension as a systolic BP of greater or equal to 90 mmHg. While BP may vary according to the cardiovascular health of the patient and may be altered by antihypertensive medications, these values were chosen because the majority of studies^{9,11-16} investigating the effects of hypotension in adult populations use a range of 90-100 mmHg. In our study the mean field BP in the hypotensive group was 70 ± 26 mmHg which increased to 125 ± 22 mmHg by the time the patient arrived at the hospital. Within our region, the majority of EMS agencies are able to provide advanced therapy in the field, and it is likely that the improvement in BP in this group was the result of resuscitative efforts such as intravenous hydration. In the normotensive group the BP was essentially unchanged from the

prehospital measurement to arrival at the hospital. Differences in mean arrival blood pressure between groups, 125 ± 22 mmHg in the hypotensive group and 142 ± 26 mmHg in the normotensive group, while statically different, does not likely represent a clinically significant difference.

In comparison to patients in the normotensive group, patients who had hypotension in the field which resolved by time of arrival in the ED had significantly greater anatomic injury as demonstrated by doubling of ISS from a mean of 11.1 ± 9.5 to 22.0 ± 17.9. This data is also consistent with that of Codner and colleagues,¹⁶ who found in a study of urban trauma patients with hypotension in the field that resolved prior to arrival at the ED that 51% of this population had a significant injury as defined by an ISS greater than 16, and 19% had a critical injury as defined by an ISS greater than 25. In our study 58% of the hypotensive group had an ISS of greater than 16, and 30% had an ISS of greater than 25. In light of our findings and that of Codner et al¹⁶ it is reasonable to assume that field hypotension is a marker of severe injury in both urban and rural environments. In earlier work by Chan et al,¹⁷ patients with out-of-hospital hypotension were also associated with a higher ISS and greater number of femur and pelvic fractures than were patients who were not hypotensive in the field. The difference in RTS between the groups is partially explained by the study design as hypotension was needed for inclusion to the hypotensive group, and hypotension is a variable used in calculating this score.⁷ The RTS is also weighted toward GCS in order to compensate for the effect of severe head injury,⁷ as a result the lower GCS in the hypotensive group compared to the normotensive group also contributes to this difference.

Brain injury is responsible for more deaths and permanent disabilities and is more costly than any other type of trauma. The association of hypotension and worse outcome following brain injury is well-documented.^{13,18,19} These findings were also confirmed in the early period of resuscitation^{12,20} and when hypotension was transient.²¹ In our study the hypotensive group had a significantly lower GCS, and the association with hypotension may have been a contributing factor to the mortality rate.

Field and ED triage can be complex. Trauma team activation based solely on mechanism of injury has been shown to be an ineffective utilization of resources.²³ Field hypotension has been demonstrated to predict severe injury and thus has been determined to be a valid indicator of triage and trauma team activation.^{14,15} In a rural trauma system with multiple EMS agencies of varying clinical abilities, prehospital hypotension may be a triage tool that is easier to use than calculation of more complex trauma scoring systems.¹⁴ Our data support field hypotension as a marker of severe injury even in those who arrive with normotension, and therefore it may be used as a primary indicator for trauma team activation, early transfer to a higher level of care, or utilization of aeromedical resources.

Comparison of ED and hospital discharge disposition between the hypotensive and normotensive groups also supports the finding that field hypotension is a valid marker of severe injury. This data is consistent with previous work by Shapiro et al,²³ who examined

isolated prehospital hypotension in patients transported by an experienced aeromedical crew expected to have greater experience with critically ill patients and hence less variability in determination of BP. In that study patients with isolated hypotension in the field were 4.4 times more likely to die and 2.9 times more likely to require a chest or abdominal operation.

Our data suggest that field hypotension is a significant marker of severe injury in patients who arrive at the hospital with a normal blood pressure. However, our investigation has several limitations. While the retrospective nature of this study reduces the risk of bias associated with reporting a lower BP in predicting outcome, this method also resulted in exclusion of many patients who did not have appropriate documentation of field BP. The exclusion of these patients may have resulted in a selection bias. One potential explanation for failing to document field BPs was that EMS providers treating more critically injured patients were focused on other tasks. A related limitation is the small number of patients in the hypotensive group. Prior studies have demonstrated measurement of BP in an out-of-hospital environment^{2,4,10,11} may be unreliable. In our study the accuracy of BP determination in the field is unknown.

Hypotension in the field is a significant indicator of severity of injury even in those who arrive at the trauma center with a normal BP. This data also should remind all those who care for injured patients to be ever vigilant regardless of arrival BP. **NCMJ**

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Availability of Tobacco Cessation Services in Free Clinics

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Abstract

Background: This study sought to determine the availability of tobacco cessation services in free clinics.

Methods: In fall 2007, a survey was emailed to free clinics that asked respondents to indicate the availability of 13 different services recommended as part of the Treating Tobacco Use and Dependence guidelines set by the United States Public Health Service (USPHS). Seventy-two percent (n=51) of clinics responded to the survey.

Results: The majority of clinics enforce a “no tobacco use” policy inside the clinic (98%), encourage health care providers to advise patients to quit (90%), ask patients about tobacco use behavior on intake (78%), provide self-help materials (70%), and offer pharmacotherapy (eg, bupropion) for quitting (60%). Fewer clinics offer free nicotine replacement therapy (35%), display counter-advertisements in waiting areas and patient rooms (35%), have a designated staff person or volunteer to help patients quit (26%), evaluate whether health care providers offer tobacco cessation advice (30%), or have onsite tobacco cessation classes (22%). One out of 3 free clinics offer comprehensive (at least 9 of 13) tobacco cessation services using the USPHS Treating Tobacco Use and Dependence guidelines.

Limitations: Small sample size limits analytical techniques that can be applied, as well as interpretation of results.

Conclusion: Free clinics offer an excellent opportunity to reach the uninsured population for tobacco cessation. Although 1 in 3 clinics is comprehensive in its approach to reduce tobacco use among their patients, many have yet to undertake the breadth of clinic-based strategies that can promote quitting. This study serves as an opportunity and a challenge to free clinics to expand their service delivery into the area of behavioral health.

Keywords: tobacco cessation; uninsured; free clinics; charity care; PHS guidelines

Disparities in tobacco use and treatment persist despite a steady decline in tobacco use since the 1950s.¹ Individuals without health insurance are more likely to smoke than those insured through private providers (30% to 22%, respectively) and are less likely to receive smoking cessation advice from a health professional.^{2,3,4} Limited access to smoking cessation programs among the uninsured may contribute to a population's excess disease burden and poorer survival.

The clinical practice guideline *Treating Tobacco Use and Dependence* was published in June 2000 by Fiore and colleagues under the auspices of the United States Public Health Service (USPHS). Also known as the PHS guidelines, this publication reviewed in explicit detail the effectiveness and best practices of tobacco control and counseling. The PHS guidelines strongly recommend: (1) implementation of a tobacco user identification system in every clinic to recognize every smoker (eg, chart prompts, patient intake forms, provider questioning); (2) education of all clinic staff in tobacco control; (3) dedication of specific tobacco

control personnel responsible for organizing each clinic's efforts (ie, program champion); and (4) using effective, evidence-based treatments for tobacco cessation including brief or long counseling sessions as well as using evidence-based pharmacologic treatments.

Despite the development of the PHS guidelines, there have been few published reports of efforts to disseminate the guidelines in “real world” settings without dedicated support from research staff. Since tobacco use rates, tobacco attributable illnesses, and related health care costs are higher among low-income and many minority populations, tobacco cessation interventions are especially important in safety net health care systems.^{6,7}

Free clinics serve a critical role in health care delivery to America's uninsured population and offer an outlet for dissemination of tobacco cessation services. Free clinics are nonprofit, private entities that are distinct from other safety net providers in that they do not accept reimbursement from any third-party payors, do not charge patients for health care services, and rely extensively on volunteer health care professionals.^{8,9} Because free clinics often

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have free pharmacy services onsite, they may also be able to fulfill a very important role in tobacco service delivery not otherwise attainable for other safety net care systems. Currently there are at least 1700 free clinics operating nationwide and an estimated 71 free clinics in North Carolina.^{10,11}

The purpose of this paper is to examine the availability of tobacco cessation services within free clinics in North Carolina with the goal of identifying points of intervention to provide broader access to evidence-based tobacco cessation programs for the uninsured. This project was approved by the Wake Forest University School of Medicine's Institutional Review Board.

METHODS

Sample

In fall 2007, a brief survey was emailed to all free clinics that are members of the North Carolina Association of Free Clinics (n=71). In order to be a member of the Association, a free clinic must offer care to the uninsured without any cost. Fifty-one clinics (72%) responded to the survey. Responses were voluntary and anonymous.

Measures

Using *Treating Tobacco Use and Dependence* guidelines by the United States Public Health Service program, the survey inquired about the following services.⁵ Questions required a yes or no response unless otherwise indicated. The list of questions is included in Table 1.

Clinics were also asked to provide additional details that could help the researchers better understand the clinics' practices related to tobacco cessation services. These responses were in an open-ended format.

Analysis

Descriptive statistics on tobacco cessation services were computed (n=51). (See Table 2.) Clinics offering comprehensive tobacco cessation services were compared to those offering fewer services to determine if there are specific types of strategies that may be more difficult to achieve in a free clinic setting. Comprehensive status was defined as offering at least 70% (9 of 13) of the strategies identified by the PHS guidelines. Identifying "hard to achieve" services provides insight into the opportunities for expanding the scope of services offered. Quantitative data were analyzed using Stata[®] Statistical Software v7.¹²

There were 30 responses to the open-ended question about tobacco services. Although there were insufficient data to allow for a formal qualitative analysis, the responses provide important information on the opportunities and challenges faced by free clinics implementing tobacco services. These data were summarized to complement the quantitative data.

RESULTS

Thirty-three percent (17 of 51) of clinics offer at least 9 of the 13 recommended strategies set forth in the PHS guidelines for *Treating Tobacco Use and Dependence*. The clinics almost

Table 1.
Survey Questions for Free Clinics

1. Do you assess tobacco use behavior among all of your clients on your intake forms?
2. Do you offer a quit line telephone number for individuals needing more information about tobacco cessation?
3. Do you offer onsite tobacco cessation classes?
4. Do you offer "self-help" materials (brochures, pamphlets, etc.) to all patients who use tobacco?
5. Do you have any signs in your waiting rooms or patient rooms that indicate the hazards of tobacco use?
6. Do you encourage your health care professionals to advise patients to quit using tobacco?
7. Do you evaluate whether the health care professionals offer tobacco cessation advice to your patients?
8. Does your pharmacy offer nicotine replacement therapy (NRT) options to your patients? If yes, clinics were asked to describe the types of NRT available.
9. Does your pharmacy offer pharmacotherapy onsite or through a voucher program? If yes, clinics were asked to describe the types of pharmacotherapy (eg, sustained-release bupropion).
10. Do you have a staff member or volunteer who is dedicated to helping patients quit using tobacco?
11. Have you ever used any of the following agencies to obtain additional information about tobacco cessation for your clinic? American Cancer Society; American Heart Association; American Lung Association; Centers for Disease Control and Prevention; National Cancer Institute; National Heart, Lung, and Blood Institute; Cancer Information Service; The Legacy Foundation; North Carolina Department of Health and Human Services Tobacco Control Branch.

universally have a "no tobacco use" policy inside the clinic and encourage their health care providers to advise patients to quit using tobacco. Three out of 4 provide a place on intake or enrollment forms to indicate the use of tobacco products. Cessation strategies that have not been adopted by the majority of free clinics include the provision of free nicotine replacement therapy, counter-advertising, and a "no tobacco use" policy surrounding the outside of free clinics.

The clinics providing the most comprehensive services (9 or more) are more likely to be aware of "quit lines," offer onsite tobacco cessation classes, offer "self-help" materials for quitting, display counter-advertising materials, evaluate whether health care providers offer tobacco cessation advice, have a staff person specifically designated to help patients quit, and have a way for clients to access pharmacotherapy. They are also more likely to have used external agencies to obtain promotional materials about tobacco cessation. The most commonly used agencies for materials are the American Cancer Society (45%), American

Table 2.
Tobacco Cessation Services Offered in Free Clinics

	Overall N=51 %	Comprehensive (≥ 9 services) ^a N=17 %	Non-Comprehensive (n=15) N=34 %
1. Intake forms have a place to indicate whether patients use tobacco products (including cigarettes and spit tobacco)	78	94	68
2. Aware of “quit lines” (toll-free telephone numbers) for patients to receive assistance with tobacco cessation	47	76	32
3. Offers onsite tobacco cessation classes	22	53	6
4. Offers “self-help” materials such as brochures or pamphlets to patients who use tobacco	70	94	59
5. Has signs in waiting rooms or patient rooms that indicate the harms of tobacco use or the benefits of quitting	35	53	26
6. Encourages health care professionals to advise patients to quit using tobacco	90	100	85
7. Evaluates whether health care professionals offer tobacco cessation advice to their patients	30	56	18
8. Has a way for clients to access nicotine replacement therapy (either onsite or through a voucher program)	35	47	29
Types of NRT available:			
Gum	15	12	15
Patch	24	29	21
Inhaler	12	6	15
Nasal Spray	8	6	9
9. Has a way for clients to access other pharmacotherapy	58	88	44
Bupropion SR/Zyban	16	24	12
Wellbutrin SR	22	29	18
Chantix	33	53	24
10. Has a staff member or volunteer who is dedicated to helping patients quit using tobacco	26	69	6
11. Has a “no tobacco use” policy inside the clinic	98	100	97
12. Has a “no tobacco use” policy immediately surrounding the outside of the clinic	44	50	41
13. Has used any agencies to obtain additional information or promotional materials about tobacco cessation for the clinic	67	100	50

a Excessive missing data from one clinic prevented the creation of a composite measure.

Heart Association (37%), and the American Lung Association (37%). Fewer clinics use the North Carolina Department of Health and Human Services Tobacco Control Branch (24%), Centers for Disease Control and Prevention (14%), National Cancer Institute (12%), National Heart, Lung, and Blood Institute (8%), Cancer Information Service (6%), or the American Legacy Foundation (4%). See Table 2 for an overall summary of free clinic tobacco cessation services.

Responses from the open-ended question offer anecdotal, yet important, insight into the opportunities and challenges free clinics experience in implementing tobacco services. Eleven clinics reported efforts to curb tobacco use in their patient

population. Six clinics reported using various classes and 1-on-1 counseling, 3 reported using supplemental materials (eg, DVDs and pamphlets), and 3 reported using different pharmacotherapy options. However the success varied considerably by clinic. For example, smoking cessation classes receive mixed reviews among clinic directors. One clinic administrator responded positively and described offering a “weekly support group led by a volunteer (former smoker carrying an oxygen tank), [with a] volunteer physician and social worker from the health department [assisting with the program].” However, another respondent reported that “[we] sort of got burned out with cessation programs when we attempted [them] several years ago.

Patients did not respond; those who did were non-compliant.”

Nine clinics also reported a desire to learn more about tobacco cessation services that can be easily adopted and integrated into the free clinic environment, and 7 clinics reported tobacco cessation programming as a future priority. One clinic administrator said “[we] would welcome a program with an easy to follow plan.” Another respondent indicated, “It is not that we don’t want to do these programs. We haven’t had the manpower to implement these programs.” Another person stated that “our physicians counsel patients, but as of yet, we do not have a program. It is a goal, and [we] would be interested in suggestions and participating in any study.”

Finally, 4 clinics reported the need for, and use of, community agencies for tobacco cessation services. According to one respondent, “[The] local hospital and health department both offer cessation programs, so we can refer.” Another clinic administrator noted that “in order to implement a program, we need to know that the agency we refer patients to for help speak Spanish and are easy for the patients to access.”

DISCUSSION

There were approximately 320 589 visits to North Carolina’s free clinics in 2006.¹³ Most individuals seeking care in free clinics are between the ages of 18-64 and approximately 65% are women. About one-half are white, one-third are African American, and one-fifth are Hispanic. These percentages are comparable to demographics found in free clinics nationally (55.1% white, 21.8% African American, and 18.7% Hispanic).¹³

Because free clinics do not accept payment for their clinical services, they are generally autonomous health care entities free from government oversight and regulation. As such, clinics are exempt from the Joint Commission on Accreditation of Health Care Organizations guideline that requires every hospital in the United States to be smoke-free in order to gain accreditation. Clinics are also not bound by the strong recommendation that providers ask about tobacco use as part of every patient health care visit. As a result, free clinics are not under any significant external pressure to enhance tobacco prevention and cessation services.

Lack of external pressure may be one reason that the majority of clinics have not adopted the PHS guidelines strategies to reduce tobacco use among their clients. Another reason may be the lack of knowledge of the range of services that can be provided or the perceived importance of these strategies relative to other pressing health care needs of their patients.

Clinics do not need to be large or well-established to adopt many of the clinic-based tobacco cessation strategies. In fact, brochures and media can be obtained free of charge from various agencies including the National Cancer Institute, the American Cancer Society, and the American Legacy Foundation in both English and Spanish. Requiring intake forms and chart prompts to indicate tobacco-using patients are inexpensive, easy strategies to adopt, and yet they can effectively encourage providers to counsel their patients about quitting. Because the majority of tobacco cessation strategies can be easily integrated with relatively low or no cost and because the potential benefit

is so great, it is probable that clinics would be willing to adopt the strategies with greater awareness of their need. The major points of intervention for free clinics in offering comprehensive tobacco cessation services include:

- (1) Identifying strategies that can be easily integrated into each clinic’s existing organizational culture with limited initial investment.
- (2) Understanding the relative value of comprehensive tobacco cessation services in terms of likelihood of quitting for their patients.
- (3) Committing a person onsite (volunteer or paid) who is willing to embrace the goal of a comprehensive tobacco cessation program and sustain it long-term. This person would become the clinic’s program champion.

These goals are not elusive. At least 17 free clinics in North Carolina have successfully achieved comprehensive tobacco programs despite special organizational challenges faced by free clinics, and others report tobacco cessation services as an important goal for their clinic.

These data are intended to be a first step to address the need for comprehensive tobacco cessation strategies in free clinics. This study is limited in scope by not evaluating the clinics’ perceived value of offering tobacco cessation services and because of the 72% response rate. It is also limited in that it assesses free clinics’ tobacco cessation services at a single-point in time. The types of services measured in this research study (eg, “self-help” materials, tobacco cessation classes) may change over time and will depend on available resources and their perceived importance. In addition, cessation counseling is important at every visit for long-term abstinence, which requires that free clinics see patients routinely and provide counseling at every visit.¹⁴ For clinics with limited operational hours and a heavy reliance on volunteers, consistent cessation counseling may be more difficult to achieve.

The data could be enhanced if clinics maintained records on the utilization of tobacco cessation services by providers and on the success of these services in helping patients quit. Despite these limitations, these data demonstrate that free clinics are an untapped resource for organizational and individually-targeted interventions to reduce tobacco use among the uninsured in North Carolina. In addition, the data highlight at least 17 free clinics in North Carolina that are already offering a broad scope of services. These clinics could serve as “best practice” models for other free clinics interested in adopting the PHS guidelines. Given that the uninsured population is more than 1.5 times more likely to smoke than the general population and that more than 300 000 visits occur each year in North Carolina free clinics, such interventions could have a significant public health impact. **NCMJ**

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Towards a More Comprehensive Understanding of Cancer Burden in North Carolina: Priorities for Intervention

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Abstract

Objective: To apply 4 measures of population burden in examining cancer burden in North Carolina and to identify priorities for intervention.

Methods: Four measures were used: incidence, mortality, prevalence, and years of potential life lost (YPLL). The North Carolina Central Cancer Registry provided summary data on incidence and mortality and record-level data that were examined using SEER*Stat software to calculate prevalence. North Carolina vital statistics (mortality) data and life expectancy estimates stratified by age, race, and sex were used to calculate YPLL. Each cancer site was ranked according to burden for each of the 4 individual burden measures and summarized into an overall rank. Burden was examined overall and by sex and race.

Principal Findings: Four cancers—lung/bronchus, female breast, prostate, and colon/rectum—accounted for approximately 57% of the total cancer incidence, prevalence, mortality, and YPLL in North Carolina. Patterns of burden in gender and race subgroups were similar, although non-whites often had higher mortality rates than did whites despite similar incidence rates. An estimated 207 583 people were living with cancer in 2004. Breast and prostate cancer accounted for 42% of these survivors. Lung/bronchus cancer was the most severe cancer, accounting for more deaths and years of life lost than any other 5 cancers combined.

Conclusions: Each of the 4 measures provides unique insight and guidance for cancer coordination and control efforts. Lung/bronchus, female breast, prostate, and colon/rectum cancers accounted for the majority of North Carolina's cancer burden and should be priorities for intervention.

Keywords: neoplasms/epidemiology; population surveillance; prevalence; survivorship; North Carolina

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We dedicate this to our good friend, Deb Blocker, whose ever-ready smile and warm character made work on this project a pleasure, and whose untimely passing leaves an unfillable void.

The burden of cancer is substantial and increasing. As the leading cause of death among those under 85 years of age nationally,¹ cancer recently replaced heart disease as the overall leading cause of death in North Carolina.² In 2008, approximately 1.4 million people nationwide will be diagnosed with cancer, and more than 560 000 will die from it.³ North Carolina had 43 335 new cancer cases and 17 267 cancer deaths in 2005 and 2006, respectively.⁴ Cancer incidence and mortality are long-familiar measures of cancer burden and primarily reflect the diagnosis and treatment phases in the middle of the cancer care continuum.⁵ However, due to substantial improvements in prevention, early detection, and treatment, understanding the beginning of the continuum (risk assessment, primary prevention, and detection) and the end of the continuum (survivorship care and recurrence surveillance) are increasingly important for comprehensive cancer control efforts.

Since the 1970s, we have seen the 5-year survival rate for the top 15 cancers grow from 42.7% for men and 56.6% for women to 64.0% for men and 64.3% for women.⁶ Cancer survivorship has tripled during that time, with approximately 11 million Americans currently living with a cancer diagnosis.⁶ The trend in North Carolina reflects that of the nation overall, with cancer survival improving and mortality rates beginning to slow or even decline.^{1,4,7} Cancer is changing shape in terms of the populations it affects and is evolving from an acute disease of short duration to a chronic one with multiple phases of longer-term management.^{1,6} This reflects the fact that people are living longer with cancer but also points to a need for application of broader measures of cancer burden to appropriately inform cancer care coordination and planning.

For over a decade, North Carolina has been a national leader in comprehensive cancer planning.⁸ An important first step in planning for the next decade is to assess North Carolina's cancer burden.^{9,10} In this analysis, we examine North Carolina's cancer burden using 4 different measures and, in the absence of known methods for integrating burden measures, present a straightforward yet novel system for combining them into a single overall measure that identifies the most burdensome cancers and informs priorities for intervention to reduce that burden.

METHODS

Two dimensions of the population burden of cancer are examined: *disease frequency* (how often the disease occurs: incidence, prevalence), and *disease severity* (how serious the disease is: mortality, years of potential life lost). Burden was examined overall and by gender and race.

Disease Frequency Measures: Incidence and Prevalence

Incidence, the yearly number of new cancer cases, represents the burden of cancer diagnosis and initial treatment. For incidence, North Carolina Central Cancer Registry (CCR)

summary data for 2005 were examined, both as number of new cases and as rates (cases per 100 000 population, based on North Carolina's 2005 population and age-adjusted to the 2000 US population).⁴

Prevalence, the number of persons alive with cancer, combines incidence with disease survival to represent the ongoing burden of living with cancer (survivorship). For prevalence, the CCR provided person-level incidence and mortality data for 1995 through 2004, the most current years deemed complete and internally consistent. These data were merged with North Carolina population estimates for the same years from the Surveillance Epidemiology and End Results (SEER) state population estimates using 4 expanded races (white, black, American Indian/Alaska Native, Asian/Pacific Islander) and single ages (0-85+).¹¹ Using SEER*Stat software,¹² the counting method of prevalence estimation was used based on the first primary cancer in the database.¹³ Limited-duration prevalence was estimated for the most extended period possible: 9.5 years.

Disease Severity Measures: Mortality and Years of Potential Life Lost

Mortality, the yearly number of deaths from cancer, represents the loss of life attributable to cancer. To examine mortality, CCR summary data for year 2006 were examined, both as number of cases and as rates (deaths per 100 000 population, based on North Carolina's 2006 population and age-adjusted to the 2000 US population).

Years of potential life lost (YPLL), the difference in years between actual and expected lifespan, quantifies the number of years of life lost prematurely due to cancer. To determine YPLL, we obtained individual-level mortality records for 2006 from North Carolina vital statistics files and used ICD-10 codes to identify deaths attributable to cancer.¹⁴ Life expectancy estimates for the years 1996–2000 stratified by age, race, and sex were obtained from the North Carolina State Center for Health Statistics.¹⁵ YPLL was calculated for each cancer death by subtracting each individual's actual age at death from his/her age-, race-, and gender-specific expected age at death. YPLL for each cancer type was calculated by summing the YPLL for all individuals who died from each cancer.

Burden Ranking and Summary Measure

For each of the 4 measures of burden, each cancer site was ranked based on its relative relationship to all other cancers. Incidence and mortality were ranked by the number of new cases and number of deaths, accordingly; prevalence was ranked by the number of people living with each cancer; and YPLL was ranked by the total estimated years of life lost to each cancer. The 10 most burdensome cancers were then scored on a scale of 1 to 10 for each of the 4 measures of burden, with the most burdensome site receiving a score of 10, descending to the 10th most burdensome site, which received a score of 1. Each cancer site's scores were then summed across the 4 measures to create summary scores for disease frequency (incidence and prevalence scores), disease severity (mortality and YPLL scores), and total burden (all 4 scores summed). Scores were thus used

to determine relative burden and are presented by each cancer site. (See Table 4.)

RESULTS

Overall Population. North Carolina's overall cancer incidence rate was 492.2 cases per 100 000 persons (492.2/100 000), with 43 335 new cases in 2005. (See Table 1.) An estimated 207 583 persons diagnosed with cancer between 1995 and 2004 were alive with the disease in July 2004. The overall cancer mortality rate was 192.6 deaths per 100 000 persons (192.6/100 000), resulting in 17 267 deaths and an estimated 233 294 YPLL in 2006.

A small number of sites represented a substantial proportion of the cancer burden. (See Table 1.) The top 10 ranked cancer sites accounted for 72%-82% of each measure's total burden. Four cancers—lung/bronchus, female breast, prostate, and colon/rectum—accounted for 55%-60% of incident and prevalent cases and 52%-59% of cancer deaths and YPLL. All but prostate cancer ranked in the top 5 for all 4 measures. Other cancers ranked among the top 5 in any measure included melanoma (incidence, prevalence), pancreas (mortality, YPLL), and leukemia (YPLL).

The cancers of greatest frequency were prostate cancer and female breast cancer—with gender-specific incidence rates at least twice those of any other cancer—and lung/bronchus cancer. Prostate and female breast cancers were also the most prevalent, representing 41.9% of all survivors. The cancer with greatest severity was lung/bronchus cancer, accounting for 31.0% of all cancer deaths and 33.9% of all YPLL—more deaths and YPLL than any of the other 5 cancers combined.

Males by Race/Ethnicity.

In 2005, North Carolina's cancer incidence rate for males of all races was 563.3/100 000 (data not shown), resulting in 21 537 new cases—17 286 white and 4251 non-white. (See Table 2.) An estimated 100 503 men diagnosed with cancer between 1995 and 2004 were alive with the disease in July 2004. In 2006, the overall cancer mortality rate for males was 242.3/100 000, with 9127 deaths and an estimated

112.391 YPLL. Prostate, lung/bronchus, and colon/rectum cancers accounted for 54.5% of incidence, 49.3% of prevalence, 52.8% of mortality, and 54.4% of YPLL.

Patterns of cancer burden for non-white and white males were similar. Prostate, lung/bronchus, and colon/rectal cancers together accounted for half or more of the incidence, prevalence, mortality, and YPLL for each group. Prostate cancer was the most frequently diagnosed cancer for both non-whites and whites; lung/bronchus cancer was the most severe. For both groups, pancreatic cancer was among the top 5 in severity, along with leukemia for white men and liver cancer for minorities. Prostate cancer was the most prevalent cancer among men, accounting for 51.2% of non-white survivors and 36.6% of white survivors.

Disparities in cancer burden existed between the 2 groups. Mortality for non-white males was 1.33 times that of whites (306.7 vs. 231.2/100 000); incidence was 1.08 times greater (596.4 vs. 550.1/100 000). Prostate cancer mortality among non-white males was 2.90 times that of whites; incidence was 1.63

Table 1.
Cancer Burden in North Carolina: Leading Sites for All Races and Sexes, by Measure

Rank	Site	Incidence - 2005*		Prevalence - July 1, 2004**	
		Count	Rate	Site	Persons
1	Breast (Female)	7098	(147.5)	Breast (Female)	47 462
2	Lung/Bronchus	6699	(76.4)	Prostate	39 581
3	Prostate	5780	(147.8)	Colon/Rectum	23 920
4	Colon/Rectum	4264	(48.8)	Lung/Bronchus	13 975
5	Melanoma	1702	(19.4)	Melanoma	12 064
6	Bladder	1686	(19.5)	Bladder	9430
7	NH Lymphoma	1553	(17.8)	NH Lymphoma	7182
8	Kidney	1422	(16.0)	Corpus Uteri	6063
9	Endocrine	1062	(12.1)	Kidney/Renal Pelvis	5741
10	Oral Cavity	1019	(11.4)	Oral Cavity	4207
	Top 10 (#)	32 285		Top 10 (#)	169 625
	All Cancers (#)	43 335		All Cancers (#)	207 583
	Top 10 (%)	74.5%		Top 10 (%)	81.7%
		Mortality - 2006*		Years of Potential Life Lost - 2006***	
Rank	Site	Count	Rate	Site	Years
1	Lung/Bronchus	5355	(59.6)	Lung/Bronchus	79 167
2	Colon/Rectum	1497	(16.7)	Breast (Female)	23 235
3	Breast (Female)	1238	(23.9)	Colon/Rectum	21 282
4	Pancreas	1012	(11.2)	Pancreas	14 402
5	Prostate	902	(27.6)	Leukemia	10 350
6	Leukemia	649	(7.4)	NH Lymphoma	8 441
7	NH Lymphoma	588	(6.7)	Prostate	7825
8	Liver	448	(4.9)	Brain/Other CNS	7487
9	Ovary	418	(8.0)	Liver	7382
10	Esophagous	401	(4.4)	Ovary	7045
	Top 10 (#)	12 508		Top 10 (#)	186 615
	All Cancers (#)	17 267		All Cancers (#)	233 294
	Top 10 (%)	72.4%		Top 10 (%)	80.0%

*Incidence and mortality rates are age-adjusted to the US 2000 Census; Incidence data for breast cancer include in situ cases.

**9.5-year prevalence estimates are used.

***Data are for white and African American populations only.

Cancer sites ranked for each measure as follows: Incidence and mortality by count; prevalence by number of persons alive with a history of cancer; YPLL by total years of life lost. Rates for female breast, ovary, corpus uteri, and prostate are based on the gender-specific population.

Table 2.
Male Cancer Burden in North Carolina: Leading Sites by Race, By Measure

White				
Rank	Incidence* Site Cases (Rate)	Prevalence** Site Persons	Mortality* Site Deaths (Rate)	YPLL*** Site Years
1	Prostate 4253 (132.0)	Prostate 29 839	Lung/Bronchus 2521 (80.5)	Lung/Bronchus 34 273
2	Lung/Bronchus 3135 (101.1)	Colon/Rectum 9803	Prostate 574 (21.4)	Colorectal 8054
3	Colon/Rectum 1765 (56.9)	Urinary Bladder 6495	Colon/Rectum 585 (18.9)	Pancreas 5502
4	Bladder 1133 (37.7)	Lung/Bronchus 460	Pancreas 404 (12.8)	Prostate 4713
5	Melanoma 920 (29.0)	Melanoma 6,437	Leukemia 320 (10.8)	Leukemia 4586
Top 5 (#)	11 206	59 034	4404	57 128
All Cancers (#)	17 286	81 505	7111	88 113
Top 5 (%)	64.8%	72.4%	61.9%	64.8%
Minority				
Rank	Incidence* Site Cases (Rate)	Prevalence** Site Persons	Mortality* Site Deaths (Rate)	YPLL*** Site Years
1	Prostate 1478 (214.5)	Prostate 9739	Lung/Bronchus 629 (93.1)	Lung/Bronchus 8538
2	Lung/Bronchus 694 (101.0)	Colon/Rectum 2080	Prostate 328 (62.0)	Prostate 2946
3	Colon/Rectum 420 (59.7)	Lung/Bronchus 1353	Colon/Rectum 184 (27.8)	Colorectal 2577
4	Kidney 173 (22.4)	Kidney/Renal Pelvis 679	Pancreas 108 (15.6)	Pancreas 1570
5	Oral Cavity 167 (20.7)	NH Lymphoma 588	Liver 76 (27.8)	Liver 1146
Top 5 (#)	2932	14 439	1325	16 777
All Cancers (#)	4251	18 998	2016	24 278
Top 5 (%)	69.0%	76.9%	65.7%	69.1%

*Incidence and mortality rates are age-adjusted to the US 2000 Census; Incidence data for breast cancer include in situ cases.

**9.5-year prevalence estimates are used.

***Data are for white and African American populations only.

Cancer sites ranked for each measure as follows: Incidence and mortality by count; prevalence by number of persons alive with a history of cancer; YPLL by total years of life lost. Rates for female breast, ovary, corpus uteri, and prostate are based on the gender-specific population.

times greater. Non-whites had higher mortality for lung/bronchus (ratio: 1.16) and colon/rectum (1.47) cancers despite having similar incidence rates (1.00 and 1.05, respectively).

Females by Race/Ethnicity. In 2005, North Carolina's cancer incidence rate for females was 447.0/100 000, resulting in 21 640 new cases. (See Table 3.) An estimated 107 080 women diagnosed with cancer between 1995 and 2004 were alive with the disease in July 2004. In 2006, the cancer mortality rate for females was 156.2/100 000 resulting in 8140 deaths and an estimated 117 349 YPLL. Breast, lung/bronchus, and colon/rectum cancers accounted for 56% of incidence, 61% of prevalence, 51% of mortality, and 58% of YPLL.

Patterns of cancer burden for non-white and white females were similar. Breast, lung/bronchus, and colon/rectum cancers accounted for half or more of the incidence, prevalence, mortality, and YPLL for each racial group. Breast cancer was the most frequent cancer for both non-whites and whites. Lung/bronchus cancer was the most severe for whites and was tied with breast cancer as the most severe among non-whites. Uterine cancer was

among the 5 most frequent cancers in both groups, while melanoma was in the top 5 for whites and cervical and endocrine cancers were for non-whites. Pancreatic and ovarian cancers were among the top 5 in mortality and YPLL for both groups, while minority women also included uterine cancer. Breast cancer was the most prevalent cancer in both race/ethnicity groups, accounting for 44.4% of non-white and 44.0% of non-white survivors.

Disparities in cancer burden for females also existed. Mortality for non-white females was 1.10 times that of whites (169.3 vs. 153.8/100 000) despite incidence that was 0.91 times that of whites (414.7 vs. 453.6/100 000). Lung/bronchus cancer was the most severe for both groups, with breast cancer also ranking first (tied) for non-white women. Lung cancer incidence and mortality rates for white women were both 1.38 times greater than those for non-white women. Breast cancer mortality among non-whites was 1.40 times greater than that of whites, despite incidence that was 0.95 times that of whites. Colon/rectal cancer incidence

and mortality rates for non-white women were 1.18 and 1.52 times greater than those of white women. Mortality for pancreatic cancer was 1.71 times greater for non-whites than whites.

Summary Burden. Overall, 4 cancers—lung/bronchus, female breast, prostate, and colon/rectal—ranked substantially ahead of other cancers in summary cancer burden. (See Table 4.) Among them, lung/bronchus and colon/rectal rank higher in severity than frequency, while female breast and prostate cancers ranked higher in frequency than severity. In rank order, non-Hodgkin's lymphoma, pancreatic cancer, melanoma, leukemia, bladder, and kidney and liver cancers (the last 2 tied for 10th) were the next most burdensome cancers, with all but non-Hodgkin's lymphoma having a polar weighting in their burden—either 100% due to frequency or 100% due to severity.

DISCUSSION

As cancer continues to evolve from an acute disease of short duration to a chronic disease with multiple phases of longer-term

Table 3.
Female Cancer Burden in North Carolina: Leading Sites by Race,
By Measure

White				
Rank	Incidence* Site Cases (Rate)	Prevalence** Site Persons	Mortality* Site Deaths (Rate)	YPLL*** Site Years
1	Breast 5587 (148.3)	Breast 38 796	Lung/Bronchus 1868 (45.5)	Lung/Bronchus 29,904
2	Lung/Bronchus 2404 (61.0)	Colon/Rectum 9414	Breast 907 (22.1)	Breast 16,057
3	Colon/Rectum 1586 (40.0)	Melanoma 5355	Colon/Rectum 533 (12.5)	Colorectal 7,350
4	Corpus Uteri 799 (20.7)	Lung/Bronchus 5288	Pancreas 354 (8.4)	Ovary 5,562
5	Melanoma 731 (20.5)	Corpus Uteri 5101	Ovary 341 (8.2)	Pancreas 5,054
Top 5 (#)	11 107	63 954	4003	63,927
All Cancers (#)	17 269	88 156	6392	90,949
Top 5 (%)	64.3%	72.5%	62.6%	70.3%

Minority				
Rank	Incidence* Site Cases (Rate)	Prevalence** Site Persons	Mortality* Site Deaths (Rate)	YPLL*** Site Years
1	Breast 1482 (141.0)	Breast 8404	Lung/Bronchus 337 (32.9)	Breast 6618
2	Colon/Rectum 471 (47.1)	Colon/Rectum 2623	Breast 331 (30.9)	Lung/Bronchus 5590
3	Lung/Bronchus 438 (44.2)	Corpus Uteri 962	Colon/Rectum 195 (19.0)	Colorectal 3069
4	Corpus Uteri 200 (20.2)	Lung/Bronchus 874	Pancreas 146 (14.4)	Pancreas 2100
5	Endocrine 165 (14.9)	Cervix Uteri 713	Corpus Uteri 81 (8.3)	Ovary 1412
Top 5 (#)	2756	13 576	1090	18 788
All Cancers (#)	4253	18 924	1748	26 400
Top 5 (%)	64.8%	71.7%	62.4%	71.2%

*Incidence and mortality rates are age-adjusted to the US 2000 Census; Incidence data for breast cancer include in situ cases.

**9.5-year prevalence estimates are used.

***Data are for white and African American populations only.

Cancer sites ranked for each measure as follows: Incidence and mortality by count; prevalence by number of persons alive with a history of cancer; YPLL by total years of life lost. Rates for female breast, ovary, corpus uteri, and prostate are based on the gender-specific population.

management,¹⁶ it is increasingly the case that no single metric adequately captures cancer burden. Accordingly, we used 4 measures—2 for disease frequency (incidence, prevalence) and 2 for disease severity (mortality, YPLL)—to assess cancer burden in North Carolina. A summary measure combining the 4 individual measures emphasizes the relative dominance of 4 cancers—lung/bronchus, female breast, prostate, and colon/rectum cancers—that together account for the majority of cancer burden (55%-60% of disease frequency; 52%-59% of disease severity).

This analysis added 2 measures—cancer prevalence and years of potential life lost (YPLL)—to the familiar measures of incidence and mortality. With the growing relevance of survivorship, prevalence is an increasingly important measure of cancer burden. Compared to people with no history of cancer, survivors tend to have poorer overall health and increased medical care use for ongoing follow-up and surveillance services.^{6,16,17} Knowing the extent of cancer-specific prevalence can help identify needs

for ongoing care, tertiary prevention, monitoring, and psychosocial support, as well as targeted prevention and early detection for these individuals and their families and caregivers.

Whereas data from SEER registries are the basis for many prevalence estimates, the high quality of North Carolina's CCR allows the examination of prevalence using actual North Carolina data on cancer incidence and mortality. These data reveal that an estimated 207 583 people diagnosed with cancer between 1995 and 2004 were living with cancer in July 2004, a number which has no doubt continued to grow since then. Breast and prostate cancer survivors were the greatest in number, together accounting for 42% of all survivors. A previous estimate for North Carolina used a different approach and calculated a 5-year limited duration prevalence (1990-1994), but found a similar distribution of survivors for the 4 major cancers.¹⁸ Similar to other limited-duration prevalence estimates, our 9.5-year estimate likely underestimates the number of cancer survivors by excluding long-term survivors of

childhood cancers, survivors diagnosed before 1995, and those with cancer who immigrated to North Carolina. New methods of calculating prevalence have recently been developed to correct for these causes of underestimation to yield a more complete estimate of prevalence.^{19,20} The North Carolina Comprehensive Cancer Program and the North Carolina CCR have recently initiated an intensive examination using these methods to fully leverage the strengths of our cancer registry and develop a more thorough and detailed understanding of complete prevalence and cancer survivorship in North Carolina.

Years of potential life lost (YPLL) incorporates not only the number of lives lost to cancer but also the number of years of life that were lost. Because lost productivity due to premature death is a major component in estimating the cost of disease, YPLL has been considered a surrogate for an economic measure of disease burden²¹ and is important to understand

given the changing shape of cancer. In 2000, cancer accounted for an estimated 259 318 years of potential life lost in North Carolina, ranking it first among all causes of death.²² Using similar methods as Buescher and colleagues, we estimated 233 294 years of potential life lost due to cancer in 2006, a decline of approximately 10% since 2000, likely reflecting the tremendous advances in early detection and treatment.^{1,3,6}

We also estimated YPLL by cancer site. Lung/bronchus cancer (5355 deaths; 79 167 YPLL) clearly was North Carolina's most severe cancer—no other 5 cancers combined exceeded its number of deaths or years of potential life lost. Prostate cancer ranked seventh in YPLL due primarily to late median age at diagnosis (age 67.0 years in North Carolina, 2004) and improved survival following treatment.^{1,3,6}

While the methodology employed in this analysis represents an extension of that used by Buescher,²² neither methodology adjusts for comorbidities, which could independently contribute to a shortening of individuals' lives. This would cause this

of the changes in this statistic's underlying characteristics (eg, average age at diagnosis, relative distribution of cancer diagnoses, etc.).

Examining these 4 measures yields a multifaceted understanding of cancer burden in North Carolina, although reliable, accurate data by site were lacking for detailed examinations of many individual race/ethnic groups as well as for other measures of burden such as quality adjusted life years and cost of illness. North Carolina's non-white population is primarily (>80%) African American, but the state has one of the nation's fastest growing Hispanic populations, and in the coming decades Hispanics with cancer will contribute more significantly to the cancer burden.²⁴ Significant differences in non-white/white mortality despite similar incidence suggest the need to examine early detection and treatment patterns by race/ethnicity.²⁵

Cancer burden is one basis for identifying priority opportunities for intervention, but it is not the only one. For example, in this analysis cervical cancer ranked low in burden, but effective and

relatively inexpensive early detection and treatment options are widely available.²⁶ Further, the recently introduced human papillomavirus vaccination opens the door to effective primary prevention, although not without controversy.²⁷⁻²⁹ Moreover, significant disparities by race/ethnicity remain in cervical cancer burden in North Carolina.⁴ Assessing cancer burden is an important first step, but complementary emphases on trends in burden and availability of effective interventions are equally important.

The 4 cancers that account for the majority of North Carolina's cancer burden all have effective, tangible, and actionable points of intervention.³⁰ Tobacco use is the leading cause of lung cancer and is a cause of other cancers among North Carolina's top 10, as well as cardiovascular disease, the number 2 cause of death in North Carolina.^{2,31} Overall smoking rates are nearly identical between white Americans and African

Americans, with 23.1% and 23.5% respectively reporting currently smoking "daily" or "some days."³² Unhealthy diet and lack of physical activity are risk factors for colon cancer, may be related to breast and prostate cancers, and are related to other chronic diseases including heart disease and diabetes. Breast and colon cancer screening have been shown to reduce cancer mortality. Completing prescribed treatment regimens and receiving guideline-concordant care yield higher survival rates.³³ The opportunities for intervention are many.

North Carolina faces challenges in exploring opportunities to reduce burden for these 4 major cancers. In 2005, 22.6% of adults, 20.3% of high school students, and 5.8% of middle school students in North Carolina reported currently smoking cigarettes, 63% of adults reported being overweight or obese,

Table 4.
Cancer Burden: Summary and Rank, by Site

Site	Frequency Burden Score	Severity Burden Score	Total Burden Score	Overall Burden Rank
Female Breast	20	17	37	1
Lung/Bronchus	16	20	36	2
Colon/Rectum	15	17	32	3
Prostate	17	10	27	4
NH Lymphoma	8	9	17	5
Pancreas	0	14	14	6
Melanoma	12	0	12	7
Leukemia	0	11	11	8
Bladder	10	0	10	9
Kidney	5	0	5	T-10
Liver	0	5	5	T-10
Corpus Uteri	3		3	
Ovary		3	3	
Brain/Other CNS		3	3	
Endocrine	2		2	
Oral Cavity	2		2	
Esophagus		1	1	

method to slightly overestimate the YPLL due exclusively to the cancer itself. At the same time, the life-table estimates used are race-specific, and while this lends greater precision to the estimates for the whites and African Americans who comprise 95.7% of our state population,²³ it does not include others including our Native American and Asian populations. Regardless, we believe these methods are accurate and appropriate both for calculating this measure of burden and as a basis for consistent comparison because many comorbidities are sequelae from the cancer or its treatment, and moreover, this methodology uses data on the underlying cause of death (cancer) rather than immediate cause of death (eg, pneumonia) or all-cause mortality for all individuals diagnosed with cancer. The apparent decline in YPLL is good news, but merits further exploration in terms

62% did not engage in recommended levels of physical activity, and 77% ate fewer than the recommended 5 daily servings of fruits and vegetables. Appropriate use of effective cancer screening tests is increasing, although the tests remain greatly underutilized.³⁴⁻³⁹

At the same time, interventions to meet these challenges already exist. Tobacco interventions including higher excise taxes, indoor air policies, restrictions on youth access to tobacco, media campaigns, and cessation programs have been shown to reduce tobacco use among adults and prevent initiation among youth.^{40,41} The state has acted to experience some of these benefits, for example, by enacting legislation to prohibit smoking in government office buildings;⁴² however challenges remain, as local governments continue to be prohibited from enacting laws to regulate smoking that are more restrictive than state law.⁴³ There are environmental and policy interventions to promote physical activity, such as improving the safety of pedestrian environments, developing community walking trails, providing fitness equipment at worksites and community centers, and initiating outreach programs to promote their use.⁴⁴ Interventions targeting individuals and medical practices have been shown to increase cancer screening.⁴⁵⁻⁴⁷ At the same time, treatment guidelines and chemoprevention options continue to emerge as do programs supporting cancer survivors and their families/caregivers.⁴⁸⁻⁵²

CONCLUSIONS

Cancer is a multifaceted disease that imposes a substantial burden on North Carolina. As the state continues to develop its Living Cancer Plan,⁸ it faces a multitude of needs and opportunities. The 4 measures of cancer burden together provide enhanced guidance for statewide cancer coordination and control efforts, with each measure providing unique insight. No cancer should be ignored, but by focusing efforts on 4 priority cancers, North Carolina can reduce the state's overall cancer burden and continue its leadership role in statewide comprehensive cancer planning. **NCMJ**

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POLICY FORUM

Cancer in North Carolina

Introduction

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Issue Brief: Addressing the Burden of Cancer for the People of North Carolina

Walter L. Shepherd, MA

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Lynn Erdman, RN, MN, OCNS; Walter L. Shepherd, MA; Manzoor Choudry, MA

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Valerie A. Murrah, DMD, MS

The North Carolina Cancer Assistance Unit: A Resource for Low-Income, Uninsured Patients with Cancer

Amy C. Denham, MD, MPH; Janet Dail

Cancer Survivorship

Marci K. Campbell, PhD; Deborah Mayer, PhD, RN, AOCN, FAAN; Amy Abernethy, MD; Suzanne Carroll, RN, MS, AOCN

Throughout this issue we have highlighted the words of cancer survivors in North Carolina in special sections. These people are able to speak to the progress we have made in beating cancer with their stories.

INTRODUCTION

Policy Forum: *Cancer in North Carolina*

The fact that cancer is the number one cause of death in North Carolina may come as no surprise. Indeed, cancer is a villain that many of us have been fighting for some time. The topic is not new to the *North Carolina Medical Journal*; in 2001 we devoted a special issue to the topic. In that issue, we covered many of the same topics that we discuss in this current issue: the North Carolina Cancer Control Plan, cancer clinical trials, and state programs that aid uninsured cancer patients. We chose to revisit the topic because we have, as a state, decided that we will move to the forefront in the fight against cancer. When the North Carolina General Assembly created the University Cancer Research Fund we stepped into a new era where we have committed to better understand the cases of cancer and how to prevent, find, and treat the disease.

Many things remain the same. Now as then, tobacco is the leading cause of preventable cancer deaths. However, there has been some progress in decreasing tobacco use. The 2001 *NCMJ* issue reported on results from the 1999 Youth Tobacco Survey. Now, nearly 10 years later, the 2007 Youth Tobacco Survey indicates that teen smoking has dropped significantly. In 1999, 18.4% of middle school students reported current tobacco use; today that number is 4.5%. For high school students, the percentage in 1999 was 38.3%; today it is 19%. Successes with youth tobacco efforts should be applauded and lessons learned should be applied to other demographics in the state, for there is still much work to be done if we are to improve smoking rates among the rest of the population.

North Carolina has an abundance of resources for cancer patients, survivors, and their families. The state is home to many world-class cancer treatment facilities as well as excellent cancer research, much of which is highlighted in this issue of the *NCMJ*. We are also fortunate to have a dedicated health care workforce that labors day in and day out to provide the best cancer care possible. Despite all this, however, gaps in our system of care still exist for those affected by cancer. Health disparities in cancer occurrence and treatment cannot be ignored. There is still a need for greater outreach and treatment for low-income or uninsured cancer patients, as well as for minority populations that can be especially hard hit by certain forms of cancer. Concentrating efforts on prevention, appropriate screenings, and early detection for all people in the state will help in bringing about real progress in reducing both cancer incidence and prevalence.

This issue of the *Journal* highlights both the historical aspects of cancer care in the state and the current successes and challenges in providing cancer care. We've also added in the voices of people who have been touched by cancer—the survivors—to give us all a sense of how the disease can be beaten. We hope that this forum will provide a roadmap for how we can tackle this devastating disease. We hope that 7 years from now, in 2013, the *North Carolina Medical Journal* will produce another issue on cancer, only this time it will report on the incredible strides we have made as a state and we will have dethroned cancer as the number one cause of death among North Carolinians.

Thomas C. Ricketts III, PhD, MPH
Editor-in-Chief

Christine Nielsen, MPH
Managing Editor

Addressing the Burden of Cancer for the People of North Carolina

Walter L. Shepherd, MA

The bad news. Cancer is now the leading cause of death in North Carolina.¹ More than 47 North Carolinians die each day from cancer,² and nearly 119 individuals a day will hear the words, “You’ve got cancer.”³ Considering the probability that more than 1 in 3 persons will be affected by cancer during their lifetime, it is clear that this is a disease that affects virtually all of us.⁴

The good news. A great deal is being done to address the burden associated with this disease. More than ever, North Carolina is actively engaged in prevention, early detection, and care programs, and stands ready to address the needs of the growing numbers of cancer survivors.

The North Carolina Paradox

There is a paradox in North Carolina, and it is reflected in statistics that describe cancer morbidity and mortality. North Carolina is the 10th largest state in the United States with a population of more than 9 million persons.⁵ It is home to several world-class public and private universities, an outstanding community college system, and many major corporations such as IBM, GlaxoSmithKline, and Quintiles. North Carolina has 43 cancer programs approved by the Commission on Cancer of the American College of Surgeons.⁶ The programs at Duke University, the University of North Carolina at Chapel Hill, and Wake Forest University are National Cancer Institute-designated cancer centers.⁷ Several North Carolina hospitals are among the top-rated cancer hospitals in the nation.⁸ Recently, many of these institutions came together for the first meeting of North Carolina’s cancer centers in Winston-Salem, which led to the creation of the North Carolina Cancer Centers’ Collaborative.

North Carolina is also home to a significant amount of cancer research. As of July 1, 2007, the American Cancer Society funded 41 projects for more than \$17 million.⁹ As of May 1, 2008, the National Cancer Institute funded 695 projects in the state.¹⁰ Additional research funding is also provided by nonprofit groups such as Komen for the Cure and The V Foundation for

Cancer Research, and an unknown amount is contributed by the private sector (eg, pharmaceutical industries and clinical research organizations). This research translates into advances and practices that prevent, detect, and treat cancer.

Yet despite these world-class cancer resources and a relatively low cancer incidence (45th lowest in the US), we are 16th in cancer mortality. These numbers should be closer together, and the gap between them reflects poor rates of early detection and early treatment.^{11,12} There are disparities in mortality rates for

“More than 47 North Carolinians die each day from cancer, and nearly 119 individuals a day will hear the words, ‘You’ve got cancer.’”

minority populations: death rates among minorities for colon/rectum cancer are 1.4 times higher than for whites, 1.5 times higher for breast cancer, and 3.2 times higher for prostate cancer.¹³ Low-income populations are also disproportionately burdened with cancer. Twenty-five percent of North Carolina counties have poverty rates greater than 18% and one-fifth of our counties are classified as persistent poverty counties.¹⁴ From 2000 to 2003, North Carolina had the third highest poverty rate increase in the United States.¹⁴ These are just some of the possible explanations for high cancer mortality in the state.

How can a state with superb resources also have such poor outcome statistics? What can and should be done?

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Cancer Prevention and Control Activities in North Carolina: Past and Present

From the mountains to the coast, our state has a rich tradition in cancer prevention and control with the involvement of many individuals and organizations. North Carolina is a national leader in both innovation and the adoption of best practices. This issue of the *North Carolina Medical Journal* provides the opportunity to examine the prevention and control activities that seek to reduce the burden of cancer on North Carolinians and which are a part of the new tradition of caring for the people in our state.

Any history of cancer prevention and control activities in North Carolina must acknowledge the significant contributions of the American Cancer Society and the North Carolina Medical Society. These 2 organizations inaugurated formal statewide cancer control efforts beginning in 1941 with the establishment of state headquarters for the Women's Field Army of the American Society for the Control of Cancer. In 1945, these 2 organizations collaborated to encourage the North Carolina General Assembly to pass House Bill 786, which created the Division of Cancer Control and State Tumor Registry within the State Board of Health. The State Tumor Registry is an important tool in tracking the extent of our cancer burden and measuring progress. Karen L. Knight, director of the North Carolina Central Cancer Registry, and her associates describe the efforts of this dedicated cadre of professionals throughout the state who work behind the scenes to collect and process detailed data on every diagnosed case of cancer.

There was early recognition that cancer diagnosis and treatment could be a financial hardship for North Carolina citizens. Thus, House Bill 786 created the North Carolina Cancer Assistance Fund.¹⁵ This is reported to be the first such cancer control program in the country.¹⁶ The North Carolina Cancer Assistance Fund is a \$2.4 million fund that helps pay for cancer diagnosis and treatment for indigent patients. Amy C. Denham and Janet Dail contribute a commentary about the Fund, how it can be accessed, and how has it been utilized to assist those in need.

Created in 1922 by the American College of Surgeons, the Commission on Cancer (CoC) is a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care. Currently there are 43 approved cancer programs in North Carolina that are on the frontlines of providing care

and treatment. Frederick L. Greene, the national chair of the Commission, and 2 of his CoC colleagues discuss the approval process and how this process enhances the quality of cancer care in our state.

In 1957, the legislature created the Commission to Study the Cause and Control of Cancer and subsequently made it a permanent study commission in 1967. By 1991, a statewide Coalition for Cervical Cancer Control was created and a Study Commission on Cancer Prevention and Control was created in 1992. The previous study commission had become relatively inactive by this date and a new, revitalized effort was needed. During the 1993 North Carolina legislative session and following the recommendations of a legislative study commission, the North Carolina Advisory Committee on Cancer Coordination and Control was established to lead cancer prevention and control activities in the state. The Advisory Committee has 34 appointed or designated members,^a and the responsibilities of the Committee are:

- 1) To recommend to the secretary [of the Department of Health and Human Services] a plan for the statewide implementation of an interagency comprehensive coordinated cancer control program.
- 2) To identify and examine the limitations and problems associated with existing laws, regulations, programs, and services related to cancer control.
- 3) To examine the financing and access to cancer control services for North Carolina's citizens and advise the secretary on a coordinated and efficient use of resources.
- 4) To identify and review health promotion and disease prevention strategies relating to the leading causes of cancer mortality and morbidity.
- 5) To recommend standards for:
 - a. Oversight and development of cancer control services
 - b. Development and maintenance of interagency training and technical assistance in the provision of cancer control services
 - c. Program monitoring and data collection
 - d. Statewide evaluation of locally based cancer control programs
 - e. Coordination of funding sources for cancer control programs
 - f. Procedures for awarding grants to local agencies providing cancer control services¹⁸

a Members include the secretary or designee of the Department of Health and Human Services; 6 legislators; 4 cancer survivors; 4 members (1 each) from the Department of Health and Human Services, the Department of Environment and Natural Resources, the Department of Public Instruction, and the North Carolina Community College System; 4 members (1 each) from the cancer control programs at the University of North Carolina at Chapel Hill School of Medicine, the Wake Forest University Bowman Gray School of Medicine, the Duke University School of Medicine, and the East Carolina University School of Medicine; 1 oncology nurse from the North Carolina Nurses Association; 1 member of the Cancer Committee of the North Carolina Medical Society; 1 member of the Old North State Medical Society; 1 member of the American Cancer Society, North Carolina Division; 1 member of the North Carolina Hospital Association; 1 member of the North Carolina Association of Local Health Directors; 1 primary care physician licensed to practice medicine in North Carolina; 1 member of the American College of Surgeons; 1 member of the North Carolina Oncology Society; 1 member of the Association of North Carolina Cancer Registrars; 1 member of the Medical Directors of the North Carolina Association of Health Plans; and up to 4 additional members at large.¹⁹

The North Carolina Cancer Plan

In 1998, North Carolina was 1 of 5 states and 1 tribal health board to receive funding from the Centers for Disease Control and Prevention to pilot national comprehensive cancer control. A major outcome and achievement of this has been the publication and distribution of a revised North Carolina Cancer Plan. Lynn Erdman, Walter L. Shepherd, and Manzoor Choudry discuss this “blueprint” that has been developed to guide North Carolina’s statewide efforts. Abandoning the more traditional approach of 5-year plans, the North Carolina Advisory Committee on Cancer Coordination and Control has sought to create a “living plan” that has the ability to adapt as required.

In an effort to translate the North Carolina Cancer Plan into specific, local activities, 6 cancer regions have been developed with placement of field staff (1 program and 1 research) in each region. Staff conduct ongoing needs assessments; channel and coordinate research efforts; assist with development and coordination of resources; and communicate with regional and state-level agencies and organizations relative to regional needs.

Recent Cancer Control Efforts

In its 2007 session the North Carolina General Assembly did something remarkable by establishing the University Cancer Research Fund. The University of North Carolina at Chapel Hill School of Medicine and its Lineberger Comprehensive Cancer Center will receive \$25 million in FY 2007-2008—increasing to \$50 million per year beginning in 2009—to conduct cancer research and assure that the research is applied in communities in North Carolina and beyond. Michael S. O’Malley, associate director of the UNC Lineberger Comprehensive Cancer Center, and his colleagues provide an overview of the goals of the legislation and what it means to North Carolina and its citizens.

The UNC Lineberger Cancer Center has also been designated as a site for the development of a Lance Armstrong Foundation Survivorship Center of Excellence. Through successes in early detection and treatment, more individuals now survive cancer. It is estimated that there are more than 300 000 cancer survivors in North Carolina.^b However, cancer survivorship presents its own set of challenges and opportunities. Marci K. Campbell and colleagues comment on these challenges and discusses what is being done in North Carolina through outreach and awareness programs and the designation of a Lance Armstrong Foundation Survivorship Center of Excellence at the University of North Carolina at Chapel Hill. As an additional response to this need, there have been 2 statewide North Carolina Cancer Survivorship Summits with 600 participants each, held in Research Triangle Park and Winston-Salem.

^b North Carolina estimates were made by applying proportion of US survivors in 2003 to the total US population and then applying to NC population estimate. US figures obtained from the US National Cancer Institute. <http://www.cancer.gov/cancertopics/factsheet/NCI/NCI>. Published October 17, 2006. Accessed July 23, 2008. NC population data accessed at <http://www.osbm.state.nc.us/demog/ncusagr7.htm> on July 23, 2008.

“Diagnosed at age 3 (1984), had surgery in Iran to remove tumor in neck. Moved to US to have chemotherapy and radiation and have been in remission for 23 years.”

— Scott
Non-Hodgkin’s Lymphoma

For many people with cancer, participation in clinical trials may offer the best hope or be the last treatment option after other therapies have failed. John Feldmann and colleagues comment on the current status and distribution of cancer clinical trials in North Carolina. The authors present ways to promote greater awareness of, and enrollment in, clinical trials and ways to make trials more accessible. The first meeting to discuss the creation of a Web-based North Carolina Cancer Clinical Trials’ Clearinghouse took place recently in order to try to further these efforts.

Other North Carolina Efforts to Address Cancer

- Organizational meeting of the North Carolina Oncology Navigators’ Association (NCONA) to bring together those who are involved in cancer patient navigation activities.
- A statewide meeting, Conversations about Colorectal Cancer, held in Greensboro.
- Annual meeting of the National Black Leadership Initiative on Cancer, held in Durham.
- Creation of the North Carolina Lung Cancer Partnership.
- Development of working groups and/or reports on melanoma, childhood cancer, cancer in adolescents and young adults, survivorship, palliative care, clinical trials, colorectal cancer, prostate cancer, and hematological cancers.
- North Carolina’s Cancer Web Portal (www.nccancer.com). This Web site can assist patients and physicians as they face overwhelming amounts of information and resources when they initiate searches about cancer.

Although oral cancer does not make the top 10 list of cancer in North Carolina, it is a type of cancer that can be frequently prevented and easily detected. Valerie A. Murrah contributes a piece that discusses the extent of oral cancer in North Carolina—much of which can be prevented by changes in personal behaviors—and what is being done both to prevent occurrence and to provide treatment.

North Carolina has an impressive record in the adoption of legislation and policies that impact the lives of cancer patients;

however, there is still more to do. Marcus Plescia and Ashley Bell examine past policy initiatives and make recommendations for the future.

North Carolina presents a paradox in cancer care: the state has invested substantial efforts to control and treat cancer, but we continue to have unacceptably high rates of the disease and we have a way to go in getting people with cancer the best care we can provide. The elements to reach the goal of minimizing the burden of cancer are reachable and we have begun to put

the pieces into place to achieve that outcome. What we need to do is make sure those pieces fit together well and that we understand that this is a long-term battle that requires a continued and coordinated effort from all of us involved in the effort. North Carolina can become the shining beacon in the fight against cancer, leading the way in protecting our people from the disease, treating it effectively when it occurs, and supporting survivors by helping them to lead full and productive lives. **NCMJ**

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A Cancer Policy Agenda for North Carolina

Marcus Plescia, MD, MPH; Ashley Bell

Public health approaches to cancer focus on 3 areas: prevention, early detection, and elimination of health disparities. All have significant state policy applications and implications. While considerable emphasis is placed on federal policy, states play a significant role in influencing federal policy. Nearly every major policy initiative considered by Congress in the last decade was designed, tested, and improved through state experimentation. In order to further North Carolina's cancer policy agenda, we offer the following 5 areas of emphasis.

Increase Preventive Efforts

Reducing exposure to tobacco products in our society is arguably the most promising preventive intervention currently available.¹ Tobacco use is the most potent risk factor for cancer. It has been causally linked to more than 10 different types of cancer, and it is the primary cause of lung cancer, the leading cause of cancer death in both men and women.² The policy agenda for tobacco has been well-defined by the public health community. Based on sound science, recommended policy interventions include: (1) increasing the unit price of tobacco products, (2) funding comprehensive state tobacco programs, (3) providing support for those who want to quit, and (4) banning smoking in all worksites and public places.

Tobacco excise taxes are a revenue source for state governments that are strongly supported by the public, and studies have shown a public health benefit when the tax is raised by at least 10%.^{3,4} At 35 cents per pack, North Carolina currently has the sixth lowest tobacco tax in the nation.⁵ Raising this tax to the national average of \$1.14 per pack would have a profound affect on cancer rates across the state. Studies in other states have shown that for every 10% increase in the cost of cigarettes there is a 4% decrease in smoking in the general population and a 7% decrease in smoking among youth.⁴ Based on this formula, a 79 cent tax increase would decrease youth smoking rates by 17% and generate an additional \$360 million in new tax

revenues. A portion of this could be used to fund a comprehensive tobacco control effort in the state. The Centers for Disease Control and Prevention recently recommended that North Carolina increase its current level of tobacco funding by \$87 million to maximize efforts in tobacco prevention and control.⁶

In 2006, the 29th Surgeon General's Report found unequivocal evidence that regular secondhand exposure to environmental tobacco smoke increases cancer risks and is a significant occupational health hazard.⁷ Among nonsmoking restaurant and

“Nearly every major policy initiative considered by Congress in the last decade was designed, tested, and improved through state experimentation.”

bar employees, rates of lung cancer are 20 to 30 times higher than in the general public.⁷ Restaurant employees are far less likely than other workers to be protected by smoke-free workplace policies, are more likely than other employees to have these policies violated where they do exist, and are more likely to be exposed to high levels of secondhand smoke on the job.⁷ While current North Carolina law has banned smoking in state-owned buildings and schools, it does not cover employees in high-risk occupations such as restaurants and bars. Current state law also preempts policy change at the local level. Communities are explicitly constrained from enacting nonsmoking ordinances by statute. North Carolina should join the 22 states that have now passed comprehensive statewide worksite smoking bans.⁸

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Tobacco is a highly addictive product that has been extensively grown, manufactured, and marketed in North Carolina. North Carolina tobacco users should be treated with compassion and supported in their efforts to quit. In 2006, 57% of North Carolina smokers made a quit attempt.⁹ State tobacco quit lines, when combined with the use of smoking cessation medications, have been shown to triple successful quit rates.¹⁰ The US Public Health Service recommends state quit lines should serve 4-6% of smokers.¹⁰ North Carolina was one of the last states to implement a quit line in 2006, and funding is available to serve less than 1% of all smokers. Most state quit lines also provide smoking cessation medications to callers. Providing additional funding for the quit line to reach more callers and allowing the quit line to provide over the counter cessation medicines would allow the state to better meet the needs of North Carolina tobacco users who are trying to quit.

Increase Early Detection

Breast, colorectal, and prostate cancers are the second and third causes of cancer death in men and women.¹¹ Breast and colorectal cancers are highly treatable when detected early using cost-effective screening tests. Access to cancer screening is highly dependant on access to a regular health care home that is affordable, convenient, and trusted. While universal access to comprehensive health care is outside the reach of most states, states are capable of providing universal access to cost-effective cancer screening tests. The federal Breast and Cervical Cancer Control Program (BCCCP) provides grants to states to provide breast and cervical cancer screening to women who are poor and uninsured. Women who are found to have cancer are automatically eligible for Medicaid coverage to assure they get treatment. The federal program provides services for about 10% of eligible women, and at least 14 states have expanded the federal program with state appropriations to reach more of the eligible population. In 2007, North Carolina expanded the NC BCCCP program by \$2 million, allowing an additional 8000 women to be served. Ultimately these services could be provided as an entitlement, assuring access to any women who seek screening services.

North Carolina could also follow the lead of a few states that have expanded the BCCCP program to include screening for colorectal cancer and have included colorectal cancer and prostate cancer in the Medical Treatment Act, making Medicaid coverage of treatment available to those diagnosed by health care providers who participate in the screening program. Funding for the Purchase of Medical Care for Cancer program, described elsewhere in this issue, could also be expanded with a more focused mandate to assure that treatment is available for cancers identified through recognized screening programs.

Eliminate Health Disparities

Racial and ethnic minorities are more likely to be diagnosed with cancer at a later stage, suffer higher rates of complications from their treatments, and die from the condition.¹³

Differences in access to care are one important cause of these disparities. Expansion of the screening programs discussed previously can improve early detection of treatable cancers among minorities. However these programs often fail to reach minority communities because of physical barriers, limited health literacy, fear, and mistrust. Funding for targeted outreach, social marketing, expansion of rural and urban health centers, incentives for practice in underserved areas, and recruitment of minority health professionals can help increase participation in screening programs.¹⁴ Culturally competent care practices improve knowledge, trust, and self-management skills in minority patients, increasing their adherence to recommendations for additional follow-up or treatment. Federally-funded providers are required to meet 4 Culturally and Linguistically Appropriate Services (CLAS) standards. State policy could be created to develop minimum standards and encourage their use through incentives.

Reduced access to care explains some but not all health disparities. It is clear that differences in the quality of care provided to racial and ethnic minorities also play a role in cancer disparities.¹³ Health care providers must have access to good data on utilization of services and clinical outcomes in racial and ethnic groups in order to engage in quality improvement efforts to identify and address disparities. North Carolina data on health care utilization among racial and ethnic minorities are limited. State surveillance of health disparities is currently only available from birth, death, and behavior survey data. Only 55% of North Carolina hospital discharge data currently have complete race and ethnicity fields. With the exception of Medicaid and Medicare, North Carolina insurers do not routinely collect data on enrollees' race and ethnicity. Self-reported race and ethnicity data are accurate and reproducible, and North Carolina recently joined a number of states that have mandated hospital reporting of these data. Race and ethnicity reporting must be improved among all North Carolina health care providers so that disparities in cancer utilization and quality of care indicators can be identified and addressed.

Support Cancer Survivors

Early detection of treatable cancers and medical advances in treatment have improved cancer survival rates considerably. However, a cancer diagnosis is a frightening experience, especially when compounded by the inadequacies of our health care system. Many individuals who have survived cancer find themselves unable to obtain health insurance either because they are ruled ineligible or because they are unable to secure affordable policies. Many states have established high risk insurance pools so patients with preexisting or chronic medical conditions can still obtain health insurance. In 2007, North Carolina passed legislation to establish a high risk pool by 2009. However, the premiums for these policies will be substantial and potentially beyond many peoples' means. The state could increase the number of people covered in the high risk pool by providing subsidies for low-income enrollees.

Balance Investment Priorities

Health services researchers, policy experts, and health leaders place great emphasis on the importance of prevention as a well-established strategy to reduce human suffering and decrease health care costs.¹⁵ However only a small portion of every health care related dollar is spent on prevention. North Carolina has aggressively pursued federal funding to develop nationally recognized preventive health programs and become a leader in public health research. State funding has also been an important component of this success. In 2001, the state established the North Carolina Health and Wellness Trust Fund (HWTF) and directed 25% of the Tobacco Master Settlement Agreement funds to develop and implement public health and preventive interventions across the state. This resource has been an invaluable asset for state efforts in tobacco control, obesity, health disparities, and access to medications. In 2004, HWTF funds were used to support the debt burden for several new medical facilities, including a new cancer center at the University of North Carolina at Chapel Hill. This resource will be invaluable to improving cancer treatment options for North Carolinians. However, this has also reduced the limited state resources available to invest in preventive

“12 year survivor. Thank God, and to Him I give all the praise. Complete remission.”

— Bobby
Prostate Cancer

health interventions by as much as \$350 million over the next 25 years. Efforts must be made to address this.

Despite our progress, cancer has now surpassed heart disease as the leading cause of death in North Carolina.¹⁶ Policy makers and health leaders need additional information, options, and resources to impact the underlying causes of cancer and eliminate disparities. In 2007, the North Carolina General Assembly funded a historic initiative to support and expand cancer research in the state's academic institutions. In developing policy for this research agenda, academic leaders must balance investments in developing new medical treatments with increased attention to expanding the evidence base for preventive interventions and exploring additional options for screening and early detection. Such an agenda would guide our future efforts to assure a progressive public health policy agenda for cancer in North Carolina. **NCMJ**

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The North Carolina Cancer Plan: A Living Plan for the People of North Carolina

Lynn Erdman, RN, MN, OCNS; Walter L. Shepherd, MA; Manzoor Choudry, MA

In our fast moving technological society, state cancer plans need to change frequently in order to remain current. North Carolina recognized this need and rose to the challenge. We are proud to be the first state in the country to develop a “Living Plan.”

The North Carolina Cancer Plan (referred to as the Plan in this commentary) is a current and evolving document designed to grow, develop, and account for progress that is made in accomplishing its goals and objectives. The Plan creates benchmarks or goals for individual programs to strive for and tracks progress toward these goals. Changes can be made to the Plan as often as necessary to keep it relevant and useful for our state in the fight against cancer. The Plan is available online at www.nccancer.com.

History

North Carolina’s commitment to cancer prevention and control dates back to at least 75 years ago when the leadership of the North Carolina Medical Society identified cancer as a major public health issue and laid the foundation for future efforts. Shortly after World War II, the North Carolina Medical Society and the Women’s Field Army (precursor of the American Cancer Society) worked successfully to have legislation enacted that created a cancer prevention and control component within North Carolina’s

public health system. Coupled with local efforts in virtually every county of the state, many prevention, screening, and treatment programs were initiated. From then until the early 1990s, there were multiple commissions, task forces, and other officially convened groups that sought to coordinate North Carolina’s cancer fighting efforts.

Finally in 1993, legislation was enacted that formally created the North Carolina Advisory Committee on Cancer Coordination

“In order for the North Carolina Cancer Plan to become the very best guide for reducing the burden of cancer for our citizens, it is essential that there always be opportunities for involving more and more stakeholders in our processes of development and implementation.”

and Control (NCAC). The North Carolina Comprehensive Cancer Program was designated to be its operational arm. Chief among NCAC’s required duties was the development

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and implementation of a formal cancer plan for the state. Consequently, two 5-year plans were developed and published in 1996 and 2001.

New Directions

As the third 5-year plan was under development in early 2006, it was determined that a new strategy was needed. It has been said that the Plan had become “the destination and not the roadmap to get there.” From this assessment, the concept of the “Living Plan” was born. Rather than produce the traditional printed document, a more dynamic approach was adopted. The Plan had to be relevant, it had to be widely available, it had to have “buy-in” from all stakeholders, and it had to have the ability to grow, evolve, and to account for progress in meeting stated goals and objectives. It also had to be part of a process that encouraged the incorporation of comments and suggestions, thus helping the Plan to evolve.

The New Process

In order to create a new environment for Plan development, it became important to engage more participants significantly in the process. Although previous plans had included input from many stakeholders, the process was greatly expanded to reach out to more community-based organizations and individuals as well as those groups who had been involved in preparing earlier plans. It was also important to emphasize that the purpose of the Plan was to take action and not just to produce a document. Cancer survivorship (defined as beginning at the time of diagnosis and continuing through the entire cancer experience) had to be richly incorporated throughout the entire Plan. Citizens were encouraged to provide ideas for consideration and concerted efforts were made to identify and reach out to more people in the cancer community throughout the entire state. The ideas collected were then channeled to 1 of 3 subcommittees of the advisory committee—prevention, early detection, or care—for refinement and incorporation into a draft of the goals and objectives.

Supplementing this process was the creation of a national database containing over 800 goals and associated objectives gathered from virtually every state and US territory engaged in the development and implementation of cancer plans. Details from all published plans were abstracted and coded for relevant elements. This information was made available on a national Web site, www.CancerPlan.org, hosted by the Centers for Disease Control and Prevention, the National Cancer Institute, and the American Cancer Society. From this data, customized reports were created and provided to the 3 subcommittees. This activity allowed North Carolina to benefit from the collective wisdom and work of colleagues and peers throughout the country and greatly enriched the development of this state’s plan.

A draft of the new Plan was unveiled at the October 2007 meeting of the NCAC. Although more people had been included in the process, the draft plan resembled the previous

“I was diagnosed in 2006, at the age of 14, with leukemia. I went through a bone marrow transplant at Duke Hospital over Christmas. I am now turning 16 and have been in remission for over a year. I am still dealing with side effects from the treatment, but am progressing each day.”

*— Camille
Leukemia*

2 efforts and potentially had a similar outcome: a static addition to a library but not an action plan. At this point, evolving a new approach became an extremely important challenge.

Making the Transition to a “Living Plan”

The first major change that occurred was a commitment on the part of the Advisory Committee, the North Carolina Comprehensive Cancer Program, and the newly created North Carolina Cancer Partnership to embrace a different approach and to ensure that everyone’s voice was heard and given appropriate consideration. New strategies are now employed to implement this new approach, which is based upon the following principles:

- *Everyone matters.* Due consideration is given to anyone and everyone who wants to offer suggestions for the Plan’s goals, objectives, and strategies. To expand involvement, particularly from cancer survivors and caregivers, 18 work groups have been created to focus attention on specific

Table 1.
Major Themes in the North Carolina Cancer Plan

Access to Services
Alcohol Use
Cancer and the Environment
Clinical Trials
Cost and Financing
Data and Surveillance
Genetics
Health Behaviors: Nutrition, Physical Activity, Tobacco Use, and Infectious Agents
Palliative Care: Pain, Hospice, and End of Life Care
Professional Education and Awareness
Public Awareness
Site-Specific Cancers
Survivorship

cancer types, crosscutting issues (eg, disparities, clinical trials, professional education, and awareness), and populations (eg, survivorship, children, adolescents, and young adults). The work groups each prepare a report that fully describes their topic and make recommendations for planning, implementation, and policy that are transmitted to the advisory committee for subsequent incorporation in the Plan and for action.

- *Reaching out.* Countless presentations related to the North Carolina Cancer Plan have been made across the state. Additionally, from October 2007 through May 2008, approximately 3000 copies of the draft Plan have been distributed to individuals and organizations.
- *Your Plan is our Plan. Our Plan is your Plan.* Special efforts have been made to establish close ties with organizations that have a cancer agenda and to have them contribute to the North Carolina Cancer Plan and incorporate the Plan into their plans and activities. This includes organizations that provide funding for programs and projects and who have agreed to add the question, “How does your proposal relate to the North Carolina Cancer Plan?” to their requests for proposals or funding applications.
- *Do you see yourself in the Plan?* Individuals and organizations are asked this question. If they don’t see how the Plan is relevant to their mission or purpose, a request is made to tell us how we can make appropriate changes or inclusions.
- *Make change easy.* By keeping the Plan in a long-term draft form, changes can be made to reflect input from stakeholders and to incorporate rapid advancement and new knowledge in cancer prevention, early detection, and treatment.
- *Listen. Incorporate. Act.* In June 2007, approximately 150 cancer survivors, caregivers, and advocates came together and told us what was important to them and where the system could be improved. In June 2008, at a similar gathering of approximately 300 attendees, a report was delivered that described more than a dozen actions and accomplishments that had occurred as a result of what was discussed at the 2007 meeting.
- *Make the Plan accessible.* The Plan is accessible via www.nccancer.com and updates are posted as they are available. A project is currently in process that will create a Web-based, database-driven version of the Plan that will allow for individuals and organizations to create and print custom Cancer Plans based on specific factors that they select.

Evaluation

With the North Carolina Cancer Plan as our roadmap and reducing the burden of cancer as our destination, following a compass is essential. This is where evaluation and surveillance become important components of our program. Elements of the Plan must be measurable and, ultimately, efforts will be reflected in both the incidence and mortality rates of cancer in North Carolina.

Table 2.
Major Objectives Suggested in the North Carolina Cancer Plan

Creating and Enhancing Partnerships: Local, Regional, and Statewide
Determining and Implementing New Policies
Eliminating Disparities of All Types
Enhancing Professional Education and Involvement
Ensuring Health Care Access for All
Ensuring an Appropriate Workforce: Quantity, Quality, and Distribution
Increasing Data and Surveillance
Increasing Funding and Resources
Making Cancer Survivorship the Centerpiece
Making the Public More Aware and Engaged
Supporting Research and New Technology

The goals of evaluation are to determine whether particular projects or initiatives are effective and to understand why they failed or succeeded. Information from evaluation is used in planning to identify needs, define the burden of cancer, determine the prevalence of cancer-related risks, identify populations with greater needs, select strategies based on proven cancer control methods, and set appropriate goals and targets. Evaluation is also used to monitor the effectiveness of programs and progress toward goals, providing for their continued improvement. Data from evaluation and surveillance serve to educate the public, the health care community, and policy makers about cancer issues.

An evaluation protocol was created for the North Carolina Cancer Plan and the activities that flowed from it. Three different aspects are evaluated: process, impact, and outcome. Process evaluation determines the extent to which the strategies and activities proposed by the Plan are implemented as intended. This includes monitoring the planning and implementation process for the Plan as a whole as well as for individual strategies and projects. Process evaluation is used to document and analyze partner activities and provide information to improve ongoing implementation efforts.

Examples of impact evaluation include increasing access to services, changing behaviors, improving the quality of care, and achieving policy or environmental changes. The desired impacts of the Plan’s strategies are the objectives listed throughout the Plan which are measurable steps necessary to reach the Plan’s goals. In addition to evaluating and summarizing the impact of individual projects, there will be a regular review of progress toward meeting objectives.

Outcome evaluation involves systematic monitoring of defined program outcomes to assess how they change over time and the extent to which changes may be directly or indirectly

attributable to the program and its activities. Additionally, regular, systematic, and accurate assessment of the program and timely reporting of evaluation findings is important to the sustainability of the program.

In order to conduct an ongoing evaluation of the Plan, we rely upon several sources of data. First, data are collected by staff of the North Carolina Comprehensive Cancer Program and the NCAC in order to measure processes employed in the actual implementation of the Plan. These data are supplemented by impact and outcome measures that are obtained through the North Carolina Central Cancer Registry, North Carolina Behavioral Risk Factor Surveillance System (BRFSS), North Carolina Cancer Survey, National Cancer Institute's Surveillance Epidemiology and End Results (SEER), and the National Cancer Data Base (NCDB) of the Commission on Cancer of the American College of Surgeons. We also utilize special studies and research that are available for epidemiology and support for surveillance and evaluation through a contractual relationship with the School of Public Health at the University of North Carolina at Chapel Hill.

Opportunities for Involvement

In order for the North Carolina Cancer Plan to become the very best guide for reducing the burden of cancer for our citizens, it is essential that there always be opportunities for involving more stakeholders in our processes of development and implementation. Through this commentary and the other commentaries contributed to this issue of the *North Carolina Medical Journal*, we hope that more individuals will become aware of both the challenges and opportunities that cancer presents to North Carolina. We openly solicit comments, contributions, and participation. Please visit www.nccancer.com, write us an email, and join the efforts. Become involved and stay involved. Contribute to the Plan and be part of its implementation. Join us in reducing the burden of cancer for all the people of North Carolina. Be a local leader in this effort. **NCMJ**

“I have beaten the odds for more than 4 decades. After surviving cervical cancer in 1964, I then beat breast cancer. On April 18, 2001 my oncologist handed me what I considered to be a death sentence: stage IV inoperable non-small cell lung cancer in both lungs! “You might make it until Christmas,” my physician told me. Well, I have celebrated 7 Christmases since my “death sentence.” I had many rounds of chemo, 30 rounds of radiation, more chemo, and then Stereotatic Body Radiation (SBR). The last round of chemo did the trick; I have been cancer free since the last week of June 2005! It will soon be 3 years! I am still alive and kicking!”

*— Charlotte
Cervical, Breast & Lung Cancer*

“As a 59-year old, 4 year, stage III prostate cancer survivor, I feel fortunate to have a primary care physician who believes in PSA blood testing to detect prostate cancer. I have learned that my relationship with my family and friends define me as a person, not material possessions.”

*— Richard
Prostate Cancer*

Cancer Resources in North Carolina

David K. Jones; Kenisha Bethea, MPH, CHES

Cancer affects people in a number of ways in addition to the physical and mental demands of treatment. Specifically, cancer survivors—defined by the National Cancer Institute as anyone who has ever been diagnosed with cancer, as well as their family members, friends and caregivers¹—experience distress, anxiety, financial insecurity and cosmetic changes, as well as changes in mobility, communication, and cognition.^{2,3} This can lead to increased demand for occupational, emotional, legal, and financial support⁴ and in some cases these demands are more acute in underserved populations such as racial and ethnic minorities.⁵ Although there are many organizations providing these resources, finding accurate and understandable information can be a daunting and difficult undertaking.^{6,7} Two of the needs most important to those impacted by cancer are information and psychosocial support⁸—needs that often go unmet.⁹

The following is a list of resources available to anyone in North Carolina who is affected, directly or indirectly, by cancer. Although not comprehensive, this list serves as a starting point for providers, patients, and their loved ones to find the help they need, as well as for researchers to find accurate and useful data. Some of these organizations are specifically devoted to North Carolina, while others are national organizations with North Carolina chapters. Most of the organizations on this list will be helpful to those affected by all types of cancer, however there is a section devoted to the 4 most common forms of cancer in North Carolina (lung, colorectal, breast, and prostate).¹⁰ Information specific to other forms can be found through the North Carolina Comprehensive Cancer Program Web site at www.nccancer.com.

National General Cancer Resources

American Cancer Society (ACS)

In addition to providing many cancer prevention, detection, and treatment resources, the ACS administers a variety of programs for cancer patients and their loved ones. Programs include *Dietician on Call*, in which anyone can receive free nutrition counseling over the phone from a registered dietician; *Man-to-Man* in which men can find information and support specific to prostate cancer; *Look Good, Feel Better*, in which women can learn beauty techniques while undergoing treatment; and *Reach for Recovery*, in which breast cancer patients and their loved ones receive support from breast cancer survivors through face-to-face interaction or by phone.

1.800.ACS.2345

www.cancer.org

National Cancer Institute (NCI)

The NCI Web site includes detailed information on various types of cancer, including links to literature published in academic journals. The site also includes information on how to prevent, detect, and cope with cancer, as well as the ability to search for clinical trials by region and/or cancer type. There are also numerous databases and statistical tools for researchers.

1.800.4.CANCER

www.cancer.gov

United Way

Although not devoted specifically to cancer, the United Way Web site has links to more than 20 000 non-profits throughout North Carolina, including faith-based organizations. Many of these organizations are useful to those affected by cancer, including those which provide financial counseling and assistance, legal advice, and transportation.

2-1-1 (from most parts of the state)

www.nc211.org (Click “search NC 2-1-1” to access their database allowing you to search for services by county, city, or zip code)

Livestrong – Lance Armstrong Foundation

The Livestrong Web site contains links to many resources for patients and providers, including how to find personal support, network with other survivors, find clinical trials, and locate educational materials. Livestrong also runs SurvivorCare, a toll-free number at which anyone can speak to a case manager.

1.866.467.7205

www.livestrong.org

North Carolina General Cancer Resources

NC Comprehensive Cancer Program

The Comprehensive Cancer Program is a unit of the North Carolina Division of Public Health that is focused on cancer prevention and control. Their Web site provides many resources for providers, patients, and their loved ones, including educational materials and links on how to find treatment, financial assistance, and clinical trials in North Carolina. They administer the NC Cancer Assistance Unit which provides financial assistance for the treatment of low-income, uninsured patients with cancer. Participation in the program is based on income.

919.707.5300

www.nccancer.com

www.nccancerassist.com

NC Health Info

This is a searchable Web portal with information on health-related services in each of the state's 100 counties. Although the site is not specific to cancer, there is a large section on cancer resources in North Carolina, as well as sections on issues relevant to those impacted by cancer. These include insurance, nutrition, medication, stress management, and treatment services.

www.nchealthinfo.org

Duke Comprehensive Cancer Center

Durham, NC

919.684.3377

www.cancer.duke.edu

UNC Lineberger Cancer Center

Chapel Hill, NC

919.966.3036

www.cancer.med.unc.edu

Wake Forest University Baptist Medical Center Comprehensive Cancer Center

Winston-Salem, NC

336.716.7971

www1.wfubmc.edu/cancer

Other Resources for Researchers

Centers for Disease Control and Prevention (CDC)

The CDC publishes educational materials and data on many specific types of cancer, as well as on cancer in general. The CDC Web site provides links to a large number of scientific articles published in the last decade.

1.800.CDC.INFO

www.cdc.gov/cancer

Central Cancer Registry

Run by the North Carolina State Center for Health Statistics, the registry has data on all cancer cases diagnosed in North Carolina. Their Web site includes links to numerous publications using these data.

www.schs.state.nc.us/SCHS/CCR

State Cancer Profiles

This is a research tool developed by the NCI and CDC which enables users to generate data tables and interactive maps by state or type of cancer, as well as to identify peer counties throughout the state or country with similar demographics.

statecancerprofiles.cancer.gov

Resources for Specific Types of Cancer

American Lung Association of North Carolina (ALA)

The ALA provides resources on screening, early detection, treatment, public awareness, and advocacy related to lung cancer. The Web site also includes information on support groups throughout the state, air quality forecasts, and smoking cessation support.

1.800.892.5650

www.lungnc.org

National Colorectal Cancer Roundtable (NCCRT)

The NCCRT is a national coalition of public, private, and voluntary organizations providing educational and advocacy resources. The Web site also includes links to recent articles published in academic journals.

www.nccrt.org

Breast Cancer Resource Directory of North Carolina

Run by the North Carolina Institute for Public Health, this site contains many links to breast cancer resources, including general educational materials, as well as information on how cancer affects women of different ages and cultural backgrounds. Although specifically dedicated to breast cancer, much of the information is relevant for people impacted by all forms of cancer and includes topics such as insurance, legal, employment, and financial advice.

1.800.514.4860

bcresourcedirectory.org

Susan G. Komen for the Cure

This is a national organization focused on advocacy, raising money for research, and providing networking opportunities for those impacted by cancer. They support screening, treatment, and education programs throughout North Carolina and have affiliate offices in Charlotte, Durham, Hickory, and Winston-Salem.

1.800.GO.KOMEN
www.komen.org

Prostate Cancer Coalition of North Carolina (PCCNC)

PCCNC provides resources on screening, early detection, treatment, public awareness, and advocacy related to prostate cancer. Their Web site also includes contact information for support groups throughout the state, as well as how to find financial assistance and clinical trials.

919.321.0365
www.pccnc.org

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Research for North Carolina: The University Cancer Research Fund

Michael S. O'Malley, PhD; Robert Blouin, PharmD; Etta D. Pisano, MD; Barbara K. Rimer DrPH;
William L. Roper, MD, MPH; H. Shelton Earp III, MD

On November 19, 2007, the North Carolina Department of Health and Human Services announced that cancer had passed heart disease to become North Carolina's number one cause of death.¹ On February 12, 2008, Ms. Kathleen Casey-Kirschling, a retired school teacher, born one second after midnight on January 1, 1946, became the first baby boomer to receive a Social Security benefit payment.^{2,3}

Cancer currently is, and will continue to be, a major health problem for North Carolina. Our state is growing and growing older. The US Census Bureau projects that by 2030, North Carolina will be the country's seventh most populous state with more than 12 million citizens. The projected growth between 2000 and 2030 is roughly equivalent to absorbing the populace of South Carolina.⁴ Over that same period, as North Carolina's estimated 2.3 million baby boomers follow Ms. Casey-Kirschling and become eligible for benefits, the number of North Carolinians aged 65 years and older is expected to double.⁵ Because age is the leading risk factor for cancer, North Carolina's current population growth will result in a doubling of the absolute number of cancer patients and survivors, even as research and improved health care lower rates of new cancers and cancer deaths.⁶ Already North Carolina's leading cause of death, cancer will remain a daunting health challenge for the state for several decades to come.

Facing that challenge and looking to create a better future for North Carolina, the North Carolina General Assembly established the University Cancer Research Fund (UCRF) in July 2007. The UCRF promotes cancer research at the University of North Carolina at Chapel Hill (UNC) and its UNC Lineberger Comprehensive Cancer Center, the North Carolina Cancer Hospital, and the UNC Health Care System. As part of this *North Carolina Medical Journal* issue highlighting cancer in North Carolina, we describe the University Cancer Research Fund, outline its Year One priorities and plans, and briefly report on its progress.

“The UCRF promotes cancer research at the University of North Carolina at Chapel Hill and its UNC Lineberger Comprehensive Cancer Center, the North Carolina Cancer Hospital, and the UNC Health Care System.”

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The Fund

The University Cancer Research Fund's goal is to save lives and reduce suffering from cancer in North Carolina and beyond through cancer research that emphasizes 3 areas:

- *Discovery.* Creating knowledge that improves our understanding of the causes and course of cancer.
- *Innovation.* Using that new knowledge to develop new and better ways to prevent, find, and treat cancer.
- *Delivery.* Applying advances to improve cancer care, screening, and prevention across the state.

To achieve these goals, the state has invested \$25 million to the Fund during FY 2007-2008. That initial investment is set to increase to \$40 million in FY 2008-2009 and then to \$50 million in FY 2009-2010 and in subsequent years. Revenues supporting the Fund come from the Tobacco Trust (a portion of the state's 1998 Master Settlement Agreement), an increase in the tax on tobacco products other than cigarettes, and the General Fund.⁷

Established as a special revenue fund in the Office of the President of the University of North Carolina and dedicated to funding cancer research at the UNC Lineberger Comprehensive Cancer Center and UNC Hospitals, the Fund is governed by the legislatively-established Cancer Research Fund Committee.⁷ The Committee includes the president of the University of North Carolina (Erskine Bowles); the deans of the University of North Carolina at Chapel Hill Schools of Medicine (William Roper), Pharmacy (Robert Blouin), and Public Health (Barbara Rimer); the director of the UNC Lineberger Comprehensive Cancer Center (Shelton Earp); and 2 prominent, national cancer leaders selected by the Committee (Edward Benz, president and chief executive officer of the Dana-Farber Cancer Institute in Boston, MA, and John Mendelsohn, president of the University of Texas M.D. Anderson Cancer Center in Houston, TX.)

Year One Priorities and Plans

During the Fund's first year, it has accelerated cancer research by investing in scientific expertise, technology, infrastructure, and innovative research guided by 8 key strategies:

- Assess cancer in North Carolina, paying attention to disparities.
- Promote innovation in cancer prevention and early detection.
- Bring knowledge about the genetics of cancer to clinical settings.
- Turn basic research into new drugs and other cancer therapies.
- Monitor patients' early responses to therapy and speed clinical trials.
- Apply findings to offer world-class patient care across the state.

- Launch nation-leading research on cancer survivorship.
- Invest in cutting-edge researchers and innovative research ideas.

These initial strategies, which capitalize on existing institutional strengths, are fundamental stepping stones to the future of cancer care, prevention, and early detection in North Carolina. We must apply our burgeoning understanding of genetics to identify people and families predisposed to cancer, find new targets for drugs, and improve patients' outcomes by tailoring treatments to the specific characteristics of their cancers. We must develop and exploit new knowledge about nanotechnology—generated at the interface of chemistry, physics, materials science, and biology—to create, evaluate, and deliver cancer drugs and imaging tests that are more effective and have fewer side effects. We must not only increase the number of cancer survivors in North Carolina, we must understand their needs and challenges so that they live better, as well as longer, with cancer. To benefit the state, we must increase access to, and quicken the pace of, clinical trials so we can identify the best new treatment, prevention, and screening techniques. Then, having identified those new best practices, we must have the ability to ensure delivery of those advances to all corners of North Carolina. Finally, we must also understand why some people do not benefit from these advances in prevention, detection, and treatment, and we must then turn that understanding into strategies to overcome those barriers that lead to disparities in outcomes.

The Fund's Year One strategies will be neither the only nor the final strategies. Cancer and cancer research are dynamic. New directions will emerge as once well-regarded approaches lead to dead ends. Development of strategic planning and evaluation processes are an integral part of the Fund's Year One priorities and plans. In addition, the Fund has conducted 6 public listening sessions across the state in Asheville, Charlotte, Greensboro, Greenville, Raleigh, and Wilmington. Informed by public input, guided by strategic planning, and monitored by an independent evaluation, the Fund will be dynamic and responsive.

First Year Progress

Although the Fund's impact on North Carolina's cancer burden will evolve over many years, we have begun to make significant progress during Year One. These initial advances are laying the foundation for long-term success.

Attracting and keeping top-notch scientific expertise in strategic areas, such as drug discovery and development, is critical to the Fund's success. This past year the Fund helped bring 2 outstanding researchers to the UNC Eshelman School of Pharmacy and the UNC Lineberger Comprehensive Cancer Center—Drs Stephen Frye and William Zamboni. By designing and synthesizing compounds, medicinal chemists bridge the gap between the therapeutic target and drug. As the worldwide head of discovery medicinal chemistry at GlaxoSmithKline, Dr Stephen Frye and his group developed Avodart and the compound that became Tykerb, a recently approved drug for advanced breast cancer. At the University of North Carolina at

Chapel Hill, Dr Frye will lead the Center for Integrative Chemical Biology and Drug Discovery. Helping move newly developed drugs into early phase clinical trials requires additional specialized expertise in clinical pharmacology and facilities. Dr William Zamboni, who came to UNC from the University of Pittsburgh Medical Center, is developing a program in translational drug development that will include establishing a Good Laboratory Practice (GLP) Analytical Facility at UNC. This GLP facility will enable researchers to assess patients' metabolism of drugs at the level required by the Federal Drug Administration (FDA). The facility, which will be the only one of its kind in the southeast, will stimulate testing of novel drugs in clinical trials both at UNC and, through collaboration, at other centers and sites.

Fund investments in new technology and equipment have also set the stage for success, both clinical and economic. Physicist Dr Otto Zhou and his colleague Dr Jianping Lu are applying carbon nanotube technology to imaging. With Fund support for equipment, Dr Zhou is building a prototype nanotube tomosynthesis 3-dimensional system for breast imaging, an approach that could lead to high-quality breast cancer screening without painful compression of the breast. Dr Zhou has also led the development of an imaging-guided radiation therapy device that allows oncologists to see the tumor in real-time during treatment. This device, which is a product of XinRay, a Research Triangle Park joint venture with Siemens Medical, will soon begin testing in clinical trials at UNC Chapel Hill.

The Fund has initiated programs and collaborations to reach out across the state. In December 2007, East Carolina University, the Brody School of Medicine, and the Leo W. Jenkins Cancer Center established a Fund-supported cancer research partnership with the University of North Carolina at Chapel Hill, the UNC School of Medicine, and the UNC Lineberger Comprehensive Cancer Center. This partnership will expand access to clinical trials and promote collaborative clinical and translational research in addition to integrating ongoing cancer research at the 2 centers. Dr Cathy Melvin, director of the UNC Lineberger's Dissemination Research Core, is leading the development of NC SPEED—Statewide Push for Excellence, Engagement, and Delivery. In a collaboration involving the Fund, the North Carolina Advisory Committee on Cancer Coordination and Control, and the American Cancer Society, NC SPEED is developing and studying methods to accelerate the movement of proven interventions from academia to communities. Also supported by the Fund, Dr Thomas Shea, UNC Lineberger associate director for clinical outreach, is working with regional centers to build effective communication and interaction that can promote dissemination of best cancer care clinical practices as well as involvement in clinical trials.

The Fund is investing in infrastructure and resources that enable cancer research. The North Carolina Central Cancer Registry is the state's data source on new cancer cases and an invaluable research partner for cancer researchers across the state. The Fund is helping the Registry enhance its data collection by

“After what I went through as a veteran woman, I want other veteran women to know they are not alone.”

*— Margo
Breast Cancer*

electronically connecting to pathology laboratories and identifying new melanoma, prostate cancer, and other cancers that are escaping the traditional hospital-based reporting system. The Fund is also establishing the UNC Survivorship Cohort Study at the University of North Carolina at Chapel Hill. Over the next 10 years, this study will identify, enroll, and monitor thousands of consenting cancer patients. Study data, which will include epidemiologic, psychosocial, clinical, and biologic measures, will provide a unique and rich resource for understanding cancer outcomes, including how to increase the quality and length of life for cancer survivors long after their treatment ends. From the current pilot effort focusing on colon cancer, the Survivorship Cohort Study plans to expand to other cancers and then partner with other institutions statewide.

The Fund is supporting and stimulating new research. The Jeanne Hopkins Lucas Breast Cancer Study, named after the North Carolina state senator who died of breast cancer in 2006, seeks to understand a deadly form of breast cancer that more often affects African American women. Led by Dr Robert Millikan and colleagues, this interdisciplinary, population-based study will be one of the largest studies of cancer racial disparities ever conducted. The Fund has also supported innovative cancer research through its 2 competitive seed grant programs, the Innovation Awards and the Clinical Innovation Awards. During Year One, these 2 programs combined have made 26 awards totaling \$2.8 million to cancer researchers.

The Fund's investments have already begun to bear dividends. The Fund's presence and commitment to cancer research has led to more than \$40 million in grants from external sources, including private philanthropy, foundations, and the National Institutes of Health.

Summary

In 2008 an estimated 40 000 North Carolinians will be diagnosed with cancer. This disease is the number one cause of death in our state and will claim more than 17 000 lives this year.⁸ North Carolina is swimming against a demographic tide of growth and aging that will bring 80 000 new cancer cases by 2050, despite continued improvements in cancer prevention, early detection, and treatment.

By establishing the University Cancer Research Fund, North Carolina has taken a bold, nation-leading step forward toward improving the future health and well-being of its citizens. Research that creates new knowledge, turns that knowledge into advances in treatment, screening, and prevention, and then ensures delivery of those advances across the state—that research is the key that unlocks the doors to a new and better future. The Fund will make that research possible.

As has often been the case, North Carolina was ahead of the national curve by creating the UCRF in July 2007. In November 2007, Texas passed a \$3 billion bond referendum to provide \$300 million annually to support cancer research over the next decade.⁹ In 2005, California passed a \$3 billion bond referendum to support stem cell research.¹⁰ Perhaps noting the downturn in federal funding for biomedical research, other states are watching these states' investments to see if they improve their citizens' health and make researchers nationally competitive. We will rigorously evaluate the UCRF to show the nation that North Carolina has taken a bold and wise step.

The North Carolina General Assembly and the people of North Carolina have presented the University of North Carolina at Chapel Hill, the UNC Lineberger Comprehensive Cancer Center, the North Carolina Cancer Hospital, and UNC Health Care with an astounding opportunity and responsibility. We embrace that opportunity and that responsibility and pledge ourselves to our shared vision of a better future for the citizens of North Carolina. **NCMJ**

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From the Tobacco Prevention and Control Branch, N.C. Department of Health and Human Services

The Commission on Cancer: Opportunities for North Carolina Cancer Care

Frederick L. Greene, MD; Terry Sarantou, MD; Leopold M. Waldenberg, MD

The Commission on Cancer (CoC) is an umbrella organization of 43 cancer organizations. (See Table 1.) Technically under the aegis of the American College of Surgeons, the CoC serves as a mechanism for communication and coordination for the majority of organizations dedicated to the multidisciplinary care of cancer patients in the United States. In addition, professional organizations representing every facet of cancer patient care have liaisons with the CoC to provide a multidisciplinary approach for modern day cancer care.

Members of the CoC include surgeons representing the American College of Surgeons as well as representatives of the 42 liaison organizations invited to membership by the Commission. The CoC is responsible for the oversight and standard setting for hospitals in the United States that dedicate their missions to outstanding cancer care. As of May 2008, there were 1480 programs which span small community hospitals, teaching hospitals, pediatric hospitals, Veterans Administration hospitals, and hospitals designated as comprehensive cancer centers under the aegis of the National Cancer Institute.¹ In the state of North Carolina there are 43 hospitals currently under the auspices of the CoC Approvals Program. These hospitals are surveyed every 3 years and must meet stringent standards dealing with clinical care, support services, research, and the development of outstanding registries for data collection relative to cancer patients.

One of the important interactions for the CoC is its alliance with the American Cancer Society (ACS). The programs which allow for cancer liaison physicians (CLPs) to be selected in each approved hospital, as well as the state liaison initiative, are under the CoC and are supported with funding from the

American Cancer Society. In addition, the Facility Information Profile System (FIPS) is a program in which basic resource data and information regarding the site and stage-specificity of hospital cases are reported to a public-use Web site. FIPS is supported by the American Cancer Society and serves as a resource to enable patients to select potential institutions for their care. It is the goal of the CoC to have each hospital update its resources and case experience and to report these to the FIPS program.

The Commission on Cancer is also dedicated to making patients aware of the importance of selecting hospitals that are committed to multidisciplinary care. During the last several years, a major public awareness campaign has been conducted

“The CoC is responsible for the oversight and standard setting for hospitals in the United States that dedicate their missions to outstanding cancer care.”

utilizing magazine advertising and notices in public arenas such as airports to explain the importance of the CoC and to urge the public to choose a CoC program for its care. In addition, public awareness campaigns dedicated to specific sites such as prostate, breast, and colorectal cancers have been conducted. These types of programs are important for planning in North Carolina and have served to focus on large groups of patients who might benefit by the CoC.

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Leopold M. Waldenberg, MD, is the past chair of the North Carolina Advisory Committee on Cancer Coordination and Control and a surveyor of the Commission on Cancer Approvals Program.

Table 1.
Commission on Cancer Member Organizations

AAHPM	American Academy of Hospice and Palliative Medicine
AAP	American Academy of Pediatrics
AACE	American Association of Cancer Education
ACS	American Cancer Society
ACOG	American College of Obstetricians and Gynecologists
ACOA	American College of Oncology Administrators
ACP	American College of Physicians
ACR	American College of Radiology
ACOSOG	American College of Surgeons Oncology Group
ACOSRAS	American College of Surgeons Resident & Associate Society
ADA	American Dietetic Association
AHNS	American Head and Neck Society
AHA	American Hospital Association
AJCC	American Joint Committee on Cancer
AMA	American Medical Association
APSA	American Pediatric Surgical Association
APOS	American Psychosocial Oncology Society
ARS	American Radium Society
ASBS	American Society of Breast Surgeons
ASCO	American Society of Clinical Oncology
ASCRS	American Society of Colon and Rectal Surgeons
ASTRO	American Society for Therapeutic Radiology and Oncology
AUA	American Urological Association
AACI	Association of American Cancer Institutes
ACE	Association of Cancer Executives
ACCC	Association of Community Cancer Centers
AOSW	Association of Oncology Social Work
CSSO	Canadian Society of Surgical Oncology
CDC	Centers for Disease Control and Prevention
CAP	College of American Pathologists
DOD	Department of Defense
VA	Department of Veterans Affairs
UICC	International Union Against Cancer
NCI	National Cancer Institute
NCRA	National Cancer Registrars Association
NCCN	National Comprehensive Cancer Network
NCBC	National Consortium of Breast Centers
NSGC	National Society of Genetic Counselors
NSABP	National Surgical Adjuvant Breast and Bowel Project
NAACCR	North American Association of Central Cancer Registries
ONS	Oncology Nursing Society
SGO	Society of Gynecologic Oncologists

In addition to these specific campaigns for patients, the CoC is committed to the recruitment of hospitals and retention of those currently in the program. Approximately 24% of all the acute care hospitals are members of the CoC. Although this is a minority of all acute care hospitals in the United States, these hospitals represent the sites for the majority—approximately 80%—of all inpatient cancer care.¹ It is important to continue to target administrators and physicians who are not yet working at CoC-approved hospital programs in order to bring their facilities into the fold.

The Commission on Cancer is also actively involved in the education of all individuals having a role in the care of cancer patients. In July 2008, the CoC hosted a national forum dedicated to the legislative and regulatory issues of cancer care. The concept was to raise awareness of health care legislation and regulatory initiatives that will affect cancer patient care. In this election year the platforms of individual candidates are particularly important not only for their overall health care agenda but also for specifics regarding cancer initiatives. Other educational offerings are held on the Internet and are excellent opportunities for all individuals involved in cancer care in North Carolina to gain better insight into issues relative to cancer patients. These educational topics deal with specific standards for the CoC approval process as well as educational offerings on cancer staging and best practices. Many of the educational offerings specifically revolve around registry concepts, since the development of a cancer registry is paramount for involvement in the CoC's approval process. To this end, a very important member of the CoC is the National Cancer Registrars Association (NCRA), which serves as an active partner in developing educational programming.

The Cancer Liaison Program is supported by significant funding from the American Cancer Society. In this program, there is a cancer liaison selected at each hospital that is approved under CoC guidance. It is the role of the cancer liaison to act as the intermediary between the national CoC organization and the individual hospitals. The cancer liaison is an important member of the cancer committee of each hospital and these physicians, made up of many specialty groups, play a major role when each hospital is surveyed on a 3-year cycle. The state of North Carolina also has a state liaison who serves to coordinate the

activities of the individual institutional liaisons. All state liaisons have an opportunity to join together at least twice a year at a national level to have meaningful interchange relative to the Cancer Liaison Program and also to interact with their American Cancer Society counterparts in their locales.

The CoC has also played an important role in the National Partnership for Comprehensive Cancer Control and has been a member since the inception of the process in 1998. The concept of comprehensive cancer control is a vision which supports a national movement that includes states, tribes, territories, and local communities working together to reduce the burden of cancer for all people. This concept is the driving force behind the state cancer plan initiative. In North Carolina, the impact of having the CoC, American Cancer Society, and many other organizations dedicated to cancer has been realized through an active cancer plan initiative. The authors of this article have all had opportunities to participate in the cancer plan initiative and have recognized the implication of having the CoC, and specifically its Approvals Program, as a highlighted goal for the North Carolina state cancer plan.

Through the CoC, the North Carolina cancer plan will be able to use the power of the National Cancer Data Base (NCDB) which was developed by the CoC and the American Cancer Society in 1988. Twenty years after its establishment there are now over 20 million cases in the NCDB.¹ This national database serves as a repository for quality data benchmarks which are being returned to the approved hospitals not only in North Carolina but throughout the United States. These benchmarks will be especially useful as the state cancer plan goes forward and we are challenged to measure our quality of cancer care against definable quality criteria. Currently each hospital in North Carolina has been asked to assess patients with stage III colon cancer who should receive adjuvant chemotherapy. In addition, quality benchmarks for breast and colorectal cancer are being measured by our North Carolina CoC-approved hospitals. The plan for the NCDB is to have registry information entered rapidly and then returned to each hospital for daily updating of its quality initiatives. Through the use of these benchmarks the state cancer plan and other agencies working in North Carolina will have the opportunity to access many facets of cancer care and compare our initiatives with other states and regions throughout the United States.

The Commission on Cancer serves as an outstanding resource and opportunity for improved cancer care throughout North Carolina. We who have been dedicated to the CoC solidly support the concept that all of our hospitals in North Carolina should become part of the Approvals Program and that all the initiatives of the Commission on Cancer should be utilized to make North Carolina a model for cancer care in the 21st century. **NCMJ**

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“At the time of my diagnosis I was 24, working my first full-time job and attending graduate school at NC State. I was on top of the world. Then the pain started—pain on my left side. It hurt to breathe, to move, to eat, it hurt to do everything. One night the pain became so excruciating that I was forced to surrender to it. I was taken to the emergency room and all I remember is the doctor telling me that they had found a tumor the size of a softball on my pancreas. I had a solid psuedopapillary tumor, documented case number 305 in the world.

The diagnosis was followed by 6 weeks of radiation and 6 weeks of chemo. After treatments were completed, I underwent a Whipple procedure. During this procedure they removed 75% of my pancreas, part of my small intestines and stomach, my duodenum and other stuff I'd never heard of. The doctors also discovered that the tumor caused the main portal vein in my liver to collapse, so emergency bypass surgery was done.

Months later, after a routine CT scan, the doctors informed me that the cancer was back, and this time it was in my stomach, with too many tumors to count. On November 4, 2005, exactly one year after my original diagnosis, a surgeon went in to remove the tumors, but much to his astonishment he couldn't find any tumors. They were gone. My family and I are convinced that this was a miracle.

So I'll end on this note: cancer is definitely not a life path that we choose for ourselves but it's one that can enrich your life and those around you, beyond measure. Make the most of what you're dealt and give others hope through your survival.”

— Amanda
Pancreatic Cancer

Cancer Clinical Trials in North Carolina

John Feldmann, MD, FACP; William R. Carpenter, PhD; Carrie Lee, MD; Thomas C. Shea, MD; James N. Atkins, MD; T. Flint Gray, MD

The field of oncology is entering a new and exciting period of discovery. For the first time, our understanding of tumor genetics and basic cell biology is leading to the rapid development of new therapies. Our ability to put these treatments to use, however, is dependent on our ability to study them in a scientific and controlled manner in clinical trials. North Carolina is a state with a very rich tradition of cancer research and patient care. We have 3 National Cancer Institute (NCI) Comprehensive Cancer Centers while 17 states have none at all. In addition, the state is the headquarters for the Southeastern Cancer Control Consortium (SCCC), the largest Community Clinical Oncology Program (CCOP) in the United States. The American Society of Clinical Oncology lists almost 600 physician members in the state and over 600 research studies are in place at nearly 250 sites. All in all, the state of North Carolina is clearly a leader in cancer care.

Yet, even with this great potential, we still struggle with the problem of enrolling North Carolinians with cancer in clinical trials. It is estimated that between 2% to 5% of the adult cancer population enrolls in cancer clinical trials nationally, and this estimate is widely cited.¹ However, this reflects only enrollment in National Cancer Institute trials and does not include studies sponsored by the pharmaceutical industry or developed locally at the university centers. Others have estimated that if all other treatment trials were included, the rate might be twice this estimate, if not higher. It is difficult, however, to confirm any of these estimates because there is a lack of reproducible methodology for measuring enrollment, a fact that

reflects the fragmented, decentralized nature of trial development and management outside of NCI trials. As a result of this system, obtaining a comprehensive estimate of total trial enrollment would require contacting many trial sponsors and having them voluntarily share their trial enrollment information—a task which is yet to meet with success.

Overall trial enrollment rates in North Carolina remain unknown, although enrollment estimates in NCI cancer treatment trials fall within the usual estimates of 2% to 5%. For the years 2002 through 2004, an average of approximately 2.5% of North Carolina adults diagnosed with cancer enrolled on NCI treatment trials.² This estimate has generally grown since the years 1995 to 1997, during which time approximately 2.1% of adults enrolled. This trend is favorable overall, but not all

“Most patients who were on clinical trials rated their experience as positive and better than standard therapy.”

populations experience enrollment equally. For example, while analysis of minority enrollment is ongoing, there is evidence that African Americans enroll in trials at a substantially lower rate than do whites.¹ There is also wide geographic variation, with greater enrollment generally seen in more urban counties

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and those served by academic medical centers. Twenty counties experience adult enrollment rates of less than 1%, including multiple counties in the southern, eastern coastal, Appalachian, and western counties. An additional 38 counties, spread broadly across the state, experience enrollment rates of 1% to 2%.

While racial and geographic differences in enrollment rates are notable, it is challenging to understand the degree to which this variation represents a problem, given our lack of information on non-NCI trial enrollment, which is likely substantial. Understanding enrollment in NCI trials is important and illuminating, but it is not a comprehensive proxy for our overall understanding of clinical trials enrollment. Indeed, a great deal of informal reports in recent years have suggested that some practices are moving away from NCI trials to participate more in industry-sponsored trials or in networks exclusively devoted to these trials. Only by understanding the total picture of trial enrollment will we be able to identify true disparities in access to clinical trials, as well as the implications for cancer care quality and what needs to be done to resolve them.

The national situation for clinical trial awareness by both physicians and patients remains a problem. Even the SCCC has struggled with this issue. The SCCC does not have a way to evaluate the efficacy of its program of promoting clinical trials to the public, so it is unclear how well any particular form of clinical trial advertising functions to educate physicians and patients who may benefit from the trials. The Harris Interactive Study of 2000 showed that only 16% of the general population is aware that clinical trials are an option, but patients who are generally unaware of the clinical trials process nevertheless had a positive impression about clinical trials in general.³ Most patients who were on clinical trials rated their experience as positive and better than standard therapy. Only 26% of those who were aware that clinical trials were an option participated in a clinical trial. Of those that went on clinical trials 60% to 75% felt that their doctors told them about the trials and made a great effort to educate them to find a trial for them. Very few of the nonparticipants felt their doctor had taken such an effort.

The SCCC itself has used a variety of techniques including billboards with the slogan "Research Cures Cancer," colorful clinical trials brochures for the public, and media presentations in several of the large markets. This reaches a limited audience at best, and the total benefit of this effort in terms of accruals is unknown.

Slightly more than 50% of North Carolina residents live in rural areas, making the state one of the most rural in the nation.⁴ Across the country, more than 80% of patients with cancer receive their care in a community setting rather than at academic medical centers. This means that clinical research, if it is to be available to all North Carolinians, must be maintained in both the community and academic settings. At the present time, community practices are struggling to participate in research even as they face rising costs and declining reimbursement.

Most oncologists are involved in clinical trial enrollment as part of their fellowship training and understand implicitly that clinical trial data serve as the basis for the appropriate prescription of therapy. However, their enthusiasm may be tempered by the

"I have stage IV pancreatic cancer. I was diagnosed December 2, 2006. I was told I had 6 months to live. I'm now working on my 17th month. I feel like I'm a survivor each and every day. I have been working full-time since the start of April 2007. I got married July 28, 2007 to a former high school girlfriend."

*— Mitch
Pancreatic Cancer*

obstacles they face, especially in setting up a new site as part of a small practice or in an underserved area. A small office must devote a significant expenditure of personnel effort, time, and expense in setting up a clinical trial operation. The clinician must also spend extra time with patients explaining the trial, often to have the patient decline or to find that an interested patient is not eligible based on a technicality. In addition, oncologist offices face penalties if they have difficulty accruing patients to an open trial or if errors in data entry occur. Given these obstacles, it might be beneficial to have an apparatus that can reach out to oncologists in small offices and underserved areas to provide support and encouragement in hopes of yielding greater clinical trial availability to all cancer patients.

With this in mind, the states' cancer community has been working on the development of a new approach: a statewide repository for clinical trials in North Carolina. This would pull together clinical trials of all types—NCI trials, clinical trials looking at new drug development with industry sponsorship, trials developed within academic medical centers, and trials looking at cancer prevention and control. This single repository, accessible online by both physicians and patients, would raise awareness of clinical research and form the backbone for future collaborative efforts between university and community practice. It would also lead to our ability to track enrollments and look for gaps in clinical trial availability in different regions of North Carolina.

A statewide Web-based repository for clinical trials is not a novel idea. This model is in practice and undergoing evaluation in other states, most notably the state of Georgia. The Georgia Center for Oncology Research and Education (CORE) created a statewide Web-based repository for clinical trials several years ago and is currently in the process of refining the system and measuring outcomes. Their Web site is managed by the Georgia CORE and the Coalition of Cancer Cooperative Groups (CCCCG). The CCCC has been instrumental in providing both the infrastructure and the powerful search engine required to update an all-inclusive listing of trials. Although the CCCC automatically updates NCI-sponsored cooperative group clinical trials and those listed in the most well-known and comprehensive national search engines, they also coordinate regular communication with the performance sites in Georgia for quality control and

completeness (ie, to ensure that trials are listed with accurate details). The North Carolina Comprehensive Cancer Plan is considering collaboration with the CCCG and also has an ongoing relationship with the Georgia CORE to learn from and model their success.

A comprehensive listing of clinical trials in North Carolina and the surrounding areas will serve many purposes. It will allow university-based practitioners to help patients locate a clinical trial at a community practice close to their home. It will also allow community practitioners to help their patients find clinical trials in an academic setting. Further, clinical trials leaders in North Carolina will have the opportunity to better understand the landscape of research in the state, identify areas of need, and guide intervention design to increase clinical trial awareness and participation. A Web-based resource would allow patients and practitioners to search for clinical trials by variables such as tumor type or stage, trial ID, zip code, or prior treatment history. No login ID will be required and the service will be available at no cost to users.

The development of such a Web-based clinical trials repository, however, will have some challenges. The 3 NCI-designated cancer centers are required to submit trial accrual data to the NCI on an annual basis, making NCI data collection relatively easy, but the same is not true for the community cancer centers. Both the NCI-designated centers and the community-based trial sites include National Cancer Institute Cooperative Group studies as well as multiple institutional and pharmaceutical company sponsored trials. While each university has its own

cancer center specific Web site, the proposed statewide Web site would offer a single location that patients, families, and physicians could explore to find the most appropriate trials available at both the university and community-based locations. Many private practices and larger community hospitals have open trials but do not maintain a centralized database that lists all their open studies, making searching difficult for interested patients and families. The challenge with the proposed Web site will be to create incentives to encourage sites to submit all their data and maintain its accuracy so that the information is up to date and functional for those accessing the Web site.

This effort was originally intended to monitor the frequency with which patients were enrolled into studies. A centralized Web site would allow identification of open studies and active sites and could eventually provide a tool to track trial accrual at each site. This is not a trivial commitment on the part of the participating centers and again leads back to the issue of how to best encourage site participation. This might be accomplished by including it as a part of a state-designated "center of excellence in oncology practice" certification that could require a certain level of trial enrollment and submission of timely data to this Web site.

The development of a central Web site for North Carolina clinical trials will place clinical research back on the radar screen for private practices, serve as a common point of information, and raise patient awareness of clinical research as an added value to cancer care and a mark of quality for participating physicians and institutions. **NCMJ**

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The Cancer Registry Profession: A Unique Role in Cancer Care and Control

Karen L. Knight, MS; Melissa Pearson, CTR; Wendy Tingle, CTR; Nora Landry, CTR; Tara Lewis, CTR; Eileen Morgan, MPA, CTR; Cathy Rimmer, MDiv, CTR

One of the unsung, and often unknown, heroes in cancer care delivery and cancer control is the cancer registrar.

Cancer registrars are trained health care professionals with the technical expertise necessary to identify reportable cancers and then abstract, code, and enter relevant demographic, diagnostic, staging, treatment, and follow-up information into a computerized database. The collected data provide cancer incidence, treatment, outcome, and trend data for public health and facility planning, development of cancer programs, quality improvement, and research activities. This commentary describes the history of the profession, its unique role in both hospitals and the North Carolina Central Cancer Registry (CCR), and its challenges for the future.

History and Evolution of a Profession

The first modern case registries for the study of cancer emerged in the early 1900s as individual physician or institutional projects. In the 1930s, surgeons in the United States began to use “Surgical Follow-Up Registries” to learn more about their surgical patients’ outcomes.¹ These early registries evolved into tumor registries which, in the early days, collected rudimentary data on cancer sites, types of surgery, and short-term and long-term outcomes and required little specialized training to follow the patients and record dates in a card file. By 1953, the American College of Surgeons’ cancer

program guidelines required all approved hospitals to have a tumor (cancer) registry.²

“The cancer registrar creates an accurate account of the health care experience of the cancer patient. All malignant diagnoses and benign tumors of the central nervous system are included.”

The Certified Tumor Registrar (CTR) credential was established in 1983 by the National Cancer Registrars Association (NCRA).³ Currently approximately 5000 registrars have earned the credential. The credentialing process assures that certified individuals have met a level of competence required to provide accurate information for cancer surveillance and research activities. The CTR credential marks achievement, fosters professional pride, and is nationally recognized in recruitment and retention of registry personnel.⁴

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Successful candidates demonstrate a standard of knowledge and field experience in the cancer registry through on-the-job training or clinical practice rotation from a formal education program. For approved cancer programs accredited by the American College of Surgeons, standards require that a CTR perform or supervise abstracting, coding, and staging activities. In order to maintain the credential, registrars are required to accrue 20 hours of continuing education credits in a 2-year cycle. This requirement promotes professional growth to keep abreast of the changes in oncology treatment including new surgical techniques, drug regimens, and radiation modalities.

The Role of a Hospital Cancer Registrar in a CoC-Approved Cancer Program

Cancer registrars are employed by hospitals with cancer programs to coordinate a variety of activities to ensure the program meets the American College of Surgeons Commission on Cancer (CoC) approval standards and state cancer reporting requirements. The standards set by the CoC are the foundation of the cancer program. Within this framework lie the day-to-day registry operations that include abstraction of cancer information, patient follow-up, quality assurance, submission of data to state and national organizations, cancer program administration, and internal and external support for those invested in the field of cancer.

The cancer registrar creates an accurate account of the health care experience of the cancer patient. All malignant diagnoses and benign tumors of the central nervous system are included. Any patient diagnosed and/or treated with a reportable neoplasm is abstracted into the registry database and then followed for the remainder of his or her lifetime. Patients who enter the facility for recurrent disease or disease management but who were diagnosed at another facility are also entered but are not followed for their lifetime. Cancer registrars collect information about each patient and each incidence of cancer including demographics, cancer identification, diagnosis, stage of disease, and treatment. Because lifetime follow-up information is maintained in the database, hospital cancer registries have the ability to provide survival data in addition to incidence data.

The cancer registrar supports all areas of an institution's cancer program through the management of certain hospital activities and through the use of its data. Cancer registrars fulfill data requests from physicians, residents, research staff, administration, students, and members of the community to support hospital initiatives including the purchase of new equipment, data to support a Certificate of Need application, implementation of new programs and support groups, and validation of the need for educational programs and staff. Registrars also perform case finding for research (prospective and retrospective epidemiologic studies) and provide data to assist in planning clinical trials and for specialized departmental research databases. In addition to facility-specific requests, the cancer registrar may provide rapid reporting to the CCR (within 1 month of diagnosis) for population-based research and may also participate in studies requested by the CoC. The cancer

registrar is instrumental in the publication of the Cancer Program Annual Report that provides hospital administration, medical staff, and the community with a summary of cases during the last year, a compilation of activities of the cancer program, and an in-depth analysis of one cancer site with a comparative survival analysis.

Hospital registrars electronically submit the data to the CCR on a monthly or quarterly basis. They also submit data to the CoC's National Cancer Data Base annually. The CoC uses the data to study patterns of care among its approved programs, and results are benchmarked with national data.

The Role of a Cancer Registrar in the Central Cancer Registry

In North Carolina, more than 200 cancer registrars and data collectors representing 120 different reporting sources report approximately 60 000 records to the Central Cancer Registry each year. Through extensive processing of these records, the CCR reports approximately 43 000 unique cases of cancer each year.⁵ Cancer registrars at the CCR consolidate multiple reports from facilities across the state, perform quality reviews, conduct audits and train staff at reporting facilities, abstract data for small facilities with no registry staff, and consult on data use and research. The CCR uses these data for population-based cancer incidence rates, research, and to plan and evaluate cancer control programs.

The CCR utilizes many resources to ensure all cases are identified and reported. Cancer registrars in CoC-approved cancer programs provide approximately 80% of all cases to the CCR. The remaining 20% must be obtained from facilities that do not have a CoC-approved cancer program including hospitals, hematology/medical oncology clinics, radiation therapy facilities, and physician practices. As the medical arena advances in technology and treatment practices, there has been an increase in cancer patients who are diagnosed and treated without entering the hospital setting. This is particularly common with melanoma and prostate cancer. Cancer registrars at the CCR are responsible for training staff at these non-registry facilities in cancer reporting. The challenges are many. In addition to high turnover, staff are usually inexperienced in cancer data collection. The CCR works closely with these facilities to provide individual training based on their level of knowledge and to provide yearly regional workshops to address changes in reporting requirements and data quality issues.

Pathology laboratories also serve as a reporting source and are required by state legislation to report to the CCR. In addition, the CCR regularly links its database with information from the state's Breast and Cervical Cancer Control Program, records from studies that use Rapid Case Ascertainment, and North Carolina Vital Records (deaths). These reports are used to identify cases that were not previously reported by other sources and to follow back to the ordering physician or facility to obtain all the information necessary to abstract the case.

A major effort of the cancer registrar at the CCR is record consolidation. This process ensures that cases of cancer are

counted only once by compiling data obtained from multiple reporting sources on the same tumor. Highly trained CTRs review each case, identify discrepancies, and consolidate the data into one record that contains the most accurate and complete information. Records describing separate, independent tumors for the same patient also need to be identified so that they can be linked to the patient but remain stored as separate cases. The task of consolidation and linkage cannot be easily automated as it involves a comparison of essentially every data item required to be collected. The final coding decision is dependent on the manual intervention and expertise of the CTR.⁶

Quality Control: Ensuring Meaningful Information

There are certain quality control activities that must take place in both hospital registries and at the CCR in order to ensure that meaningful information is available. Reconciliation of data edits is a requirement for all cancer registries. Data edits follow logical rules, typically embodied in a computer algorithm, that are applied to all records to check for item validity and consistency. An example of a failed edit would be a conflict between the primary site and histology. Re-abstracting audits are also used to retrospectively assess the level of agreement with the source document and reproducibility of registry data.

For CoC-approved cancer programs, a physician must review 10% of the cancer registry cases to assess the quality of diagnosis, stage, and treatment data. The Cancer Committee in each hospital also sets guidelines to measure data quality which are included in the review.⁷ Hospital facilities, as well as the CCR, establish an intricate array of quality measurement requirements such as a visual review of abstracted cases or generating reports designed to identify specific conflicts or common errors in the data.

Quality control involves more than correcting errors in the data. It is essential that feedback be given to abstractors on a regular basis so that recurring errors are eliminated. Elements that contributed to the errors must be analyzed and training programs targeted around these areas.

Training: An Ongoing Challenge

A standardized dataset is a valuable product of cancer registries. The primary value of these data lies in their uniformity and the ability to compare data from multiple databases. Because cancer registry data are coded in such detail, instructions are continually being evaluated and revised. Over a longer term, instructions are modified to reflect changes in medical technology, computer technology, and in the use of registry data itself. Adding to the complexity of this task are the varying requirements mandated by the standard setting organizations. The accumulation of these factors makes training new cancer registrars and keeping existing cancer registrars informed of the latest changes especially challenging.

North Carolina cancer registrars have taken a role as leaders in training and education with the development of two

“Diagnosed August 1, 2003; radiation & chemo, temporary ileostomy, liver (2) & lung resections, RFA, and still in treatment today. Colon Cancer Alliance volunteer, also active in NCCCP, 4CNC, other awareness programs. Continues to work, play golf, and practice healthy lifestyle through nutrition and exercise. THERE IS HOPE!!”

*— Gordon
Colorectal Cancer*

nationally-recognized training programs. The Association of North Carolina Cancer Registrars (ANCCR), in collaboration with the CCR, offers an intensive training program for new cancer registrars. ANCCR is the only state association to offer a training program of this magnitude. In 2006, Davidson County Community College in Lexington, North Carolina, began offering an Associate in Applied Science degree in Cancer Information Management. This program is 1 of only 4 NCRA-approved formal education programs that offer an Associate's degree in cancer registry management. Both programs were developed by and are currently taught by North Carolina cancer registrars.

Depending on the experience and education a person brings to the position, training can span many months before the person is considered to have the expected proficiency in cancer data management. The opportunity to attend a training program or a formal education program such as those offered in North Carolina not only builds cancer registrars with a stronger understanding of their responsibilities but also reduces the labor-intensive process required with on-the-job training. North Carolina cancer registrars are very active in the profession, serving in various capacities of leadership at the state and national levels, and several North Carolina cancer registrars have received state and national recognition for their contributions to the cancer registry profession.

A Profession at Risk: Recruitment and Retention of Cancer Registrars

Recruitment and retention of Certified Tumor Registrars is a unique challenge to the profession. Recruitment is challenging because the degree of specialization is great, the workforce is small, and there are few training programs available. Because of this quandary, most registrars receive the specialized training on the job. In recognition of these challenges, the education requirement for certification has been increased to include an allied health background along with 1 year of cancer registry experience. Successful retention tactics can include an emphasis on flexible hours, the ability to work from a remote environment, and most importantly, emphasis on the fact that this is not just a

job but a career with an impact on cancer surveillance and control. In addition to adequate salary compensation, opportunities for professional growth such as attendance at forums, symposiums, Webinars, and state and national meetings can improve retention. Opportunities to support health fairs, screening programs, and fundraisers allow the cancer registrar to play a more visible role and to connect with the larger community.

A hospital cancer registry does not generate revenue for the hospital, which makes it difficult to provide competitive salaries for its staff. At the CCR, the personnel classification of these positions makes it difficult to hire highly experienced CTRs at competitive rates. Recognition and respect for the CTR as part of the health care team at the hospital and the state cancer control program is essential. All the facilities, administrators, physicians, public health programs, and nonprofit agencies that benefit from the cancer registrars' efforts are encouraged to recognize their important role in the fight against cancer and to support the profession through monetary and training

resources. It is also important that data users acknowledge the registry as the source of data in presentations, publications, and other data products. This acknowledgement and support is essential to the recruitment and retention of high quality cancer registrars.

To meet the needs of the 21st century, cancer registry data has become much more complex. Cancer registrars face many challenges as they keep abreast of rapid changes in the practice of oncology and maintain the skills needed for high-quality data collection. While it is not certain exactly what the cancer registrar's job will be like in 5, 10, or 15 years, technology will play an important role. The cancer registrar must have the technological and analytical skills to ensure accurate data, efficient electronic data systems, and appropriate data use and dissemination. To meet the challenges of today, a cancer registrar uses self-training, formal education, and certification in order to serve within a field that is considered the backbone of national and local cancer surveillance efforts.³ **NCMJ**

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Dentistry and the Prevention, Diagnosis, and Treatment of Oral Cancer in North Carolina

Valerie A. Murrah, DMD, MS

The American Cancer Society estimates that in 2008 there will be 35 310 cases of oral cancer in the United States, resulting in 7590 deaths. The 5-year survival rate for localized disease is estimated at 82% and the 5-year relative survival rate for all stages combined is estimated at 59%.¹ The 5-year survival rate for metastatic disease has changed very little in the past 50 years. An analysis of state-specific trends in oral cancer epidemiology in the US has revealed the disturbing statistic that our state is 1 of 8 that have exhibited increasing rates of oral cancer deaths, according to NCI SEER data for the period from 1999-2003.² Over that time period we outrank all 50 states, except Nevada, in increased annual percent change in mortality rates for oral cancer at +4.0% (Nevada: +4.6%), the overall rate for the US being -1.1%. Analysis of increased mortality rate changes according to race and gender in North Carolina revealed the change to be occurring primarily in African American males between ages 50 and 65.²

The greatest risk factor for oral cancer is tobacco use, with the risk of developing this cancer increasing with the amount chewed and the duration of the habit. Smokers are 6 times more likely to develop oral cancer than nonsmokers. With North Carolina being the leading producer of tobacco in the nation, it is not surprising that the state ranks high in increased annual percent change in mortality rates for oral cancer. Ninety percent of patients with oral cancers use tobacco and 75% - 80% engage in frequent alcohol consumption.¹ Other risk factors include sunlight (lip cancer) and the human papillomavirus.

The fields of medicine and dentistry have differed somewhat

in their views concerning screening and early detection of oral cancer over the years. The US Preventive Task Force (USPSTF) summarized this differing view in its 2004 updated recommendations:

[There is] no new good quality evidence that screening for oral cancer leads to improved health outcomes for either high-risk adults (ie, those over the age of 50 who use tobacco) or for average-risk adults in the general population. It is unlikely that controlled trials of screening for oral cancer will ever be conducted in the general population because of the very low incidence of oral cancer in the United States compared to other malignancies. There is also no new evidence for the harm of screening. As a result, the USPSTF could not determine the balance between the benefits and harms of screening for oral cancer.^{3,4}

Interestingly, no dentists were listed among the numerous task force members. On the other hand, it may be the case that the lack of "good quality evidence" reflects a need for more extensive analysis of the issue, because the USPSTF previously had recommended in 1996 that clinical health care providers perform oral examinations for cancerous lesions in patients who use tobacco or excessive amounts of alcohol.⁵ Further evidence of the ambivalence of the medical community concerning screening was apparent in the Healthy People 2000 guidelines which advocated the goal of increasing to at least 40% the number of people age 50 or older who received an oral

“Perhaps because the dentist is always looking at small details in the mouth, dentistry has always strongly advocated oral cancer screening examinations as a part of routine dental examinations...”

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examination while visiting a primary care provider during the preceding year (objective 16.14).⁶

Perhaps because the dentist is always looking at small details in the mouth, dentistry has always strongly advocated oral cancer screening examinations as a part of routine dental examinations, believing in the ability of the practitioner to detect even minute incipient lesions. Many hours of the curriculum of dental schools have been devoted not only to teaching thorough head and neck and intraoral examination techniques, but also to the minute details of mucosal and intrabony abnormalities. As many as 90 curricular hours in oral and maxillofacial pathology and oral medicine courses of the general dentistry curriculum are devoted to detecting and diagnosing conditions that could prove to be malignant. Despite this fact and despite the ease with which this exam can be performed, data from the 1992 National Health Interview Survey-Cancer Control report showed that only 14.3% of respondents reported that they had ever been examined for oral cancer.⁶ Two explanations were proposed for these findings. First, clinical health care providers may not have received appropriate training beyond what is needed to conduct a simple oral inspection and thus do not examine or palpate for early clinical signs of oral cancer. Second, the prevalence of oral cancer examinations may be underestimated because some persons made primary care visits for reasons unlikely to prompt an examination for oral cancer and because some patients may not recall receiving an oral cancer examination, despite a prompting question. A third explanation may be that an oral cancer screening exam was done, but the patient was not informed that it had been performed.

Direct inspection and palpation of the lips, tongue, floor of mouth, buccal and alveolar mucosae, oropharynx, and tonsils are the most commonly recommended means of oral cancer screening. Palpation of lymph nodes in the head and neck should also be included. Interestingly, however, there are little data on the sensitivity and specificity of these methods.⁴ Within the past decade, a number of adjunctive techniques for oral examination have been marketed, primarily to dentists and otolaryngologists. These have claimed to increase the likelihood of identification of premalignant or malignant lesions by the clinician by either illumination techniques coupled with tissue pretreatment or by the harvesting of epithelial cells with a noninvasive brush technique. Excellent systematic reviews have recently been reported for these techniques.^{6,7} These are well-summarized by Lingen et al,⁷ who state that the tantalizing implication that such technologies may improve detection of oral cancers and precancers beyond conventional oral examination alone has yet to be rigorously confirmed.

Patton et al⁸ addressed the educational preparedness of 4 health care provider groups in North Carolina to reduce the burden of oropharyngeal cancer through effective cancer control strategies such as reducing tobacco consumption, suggesting

healthy lifestyle and diet, and performing early detection through screening examinations and appropriate follow up. Pretested surveys were mailed to random samples of licensed health care professionals. Nearly all providers agreed that early detection improves 5-year survival rates. Dental providers (584 dentists and 651 hygienists) were less likely to feel adequately trained in tobacco and alcohol cessation and the palpation of lymph nodes but were significantly more likely to perform oral cancer examinations than medical providers (273 family physicians and 294 nurse practitioners). Dental health care providers who felt adequately trained in addressing smoking and alcohol cessation were more likely to address these questions on their medical histories.

Without an adequate diagnosis of oral/pharyngeal cancer, there clearly cannot be an effective treatment plan. The gold standard for determining a diagnosis of a suspicious lesion remains the tissue biopsy and histopathological examination. In North Carolina, general dentists, oral and maxillofacial surgeons, and other surgical specialists of dentistry and medicine frequently utilize the diagnostic services of the University of North Carolina oral and maxillofacial biopsy service for tissues removed in their offices in the outpatient setting. Tissues are read by oral and maxillofacial pathologists—dentists trained in anatomic pathology—who are diplomates of the American Board of Oral and Maxillofacial Pathology and have practices that are exclusively devoted to the surgical pathology of the head and neck region. The UNC laboratory is the only CLIA-certified^a oral pathology laboratory in North Carolina and accessioned over 6800 specimens per year from the head and neck regions. The number of oral cancers and precancers accessioned annually by this lab is greatest from the Triad region of the state.

Following diagnosis, precancerous lesions and localized cancers are frequently managed by the oral and maxillofacial surgeon or other surgical specialist in dentistry. Laser surgery is a frequent modality for managing dysplastic or precancerous oral lesions. The advanced stage oral cancers are referred to otolaryngologists for final treatment. Subsequent to excision of an oral cancer, a patient may need to be referred to a maxillofacial prosthodontist. This dentist specializes in the restoration of esthetic and functional rehabilitation of the late stage oral cancer patient who may be faced with a significant surgical defect in his normal anatomic structures. Finally, the hospital dentist will be involved with the oncologist in the management of all oral cancer patients who must undergo radiation and/or chemotherapy. Carious and periodontally compromised teeth must be restored or extracted prior to the initiation of these treatment modalities.

All health care providers have the potential to reduce the morbidity and mortality from oral cancer by examination and early detection of oral precancer and cancer and subsequent timely and appropriate treatment. However, perhaps the most

a The Centers for Medicare and Medicaid Services (CMS) regulates all laboratory testing (except research) performed on humans in the US through the Clinical Laboratory Improvement Amendments (CLIA).

ground in the fight against oral cancer can be gained in our state by a commitment from all health care providers to provide patient education and counseling that will promote the ability of the patient to quit using the most powerful etiologic factor for oral cancer—tobacco. The state has stepped up to the plate in this regard by promoting QuitlineNC.^b The Quitline offers trained cessation coaches who will initiate calls to patients who have been referred, and a new fax referral option has been implemented to speed up the process. Educational materials about this service have recently been mailed to North Carolina practitioners. This initiative will allow the clinician who is reticent to undertake tobacco cessation initiatives on his/her own to turn over the educational effort to a well-trained, dedicated, and focused workforce. With greater efforts in education and prevention in both dentistry and medicine, perhaps the day will come when we will no longer have to say that 4 people per hour are diagnosed with head and neck cancer and that one person dies every hour from oral cancer. **NCMJ**

“I had a lump appear between my breasts and it turned into cancer. It was a turning point in my life, financially, emotionally, and physically. I was devastated. After I came to the understanding of how desperate this can be I decided to form a support group to help others get through. Frontline Cancer Support Group was birthed on March 22, 2007.”

*— Bertha
Breast Cancer*

^b The QuitlineNC phone number is 1-800-QUIT-NOW. Cessation coaches are available 7 days per week, from 8 am to midnight. The Web site is www.QuitlineNC.com

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The North Carolina Cancer Assistance Unit: A Resource for Low-Income, Uninsured Patients with Cancer

Amy C. Denham, MD, MPH; Janet Dail

What do you do when you are told that you have cancer and you have no insurance or money to pay for medical care? Every day in North Carolina many individuals face this exact situation. Patients diagnosed with cancer experience fear, anxiety, and emotional distress, but low-income, uninsured patients also have to contend with considerable financial stress. Each year over 40 000 North Carolinians are diagnosed with cancer, and it is estimated that 3% to 8% of these individuals do not have health insurance.

A cancer diagnosis can be financially devastating for persons without insurance and without the resources to pay for care. The diagnostic workup of a patient with suspected cancer—for example, a breast lump or an elevated PSA—might cost well over \$1000. Treatment, which could include surgery, radiation, or chemotherapy, might cost thousands of dollars. If the treatment includes targeted therapies such as monoclonal antibodies, the cost could rise to tens of thousands of dollars. Faced with these costs, families living in poverty might be forced to choose between forgoing needed care or going deep into debt.

The good news is that there is help. For over 60 years, the North Carolina Cancer Assistance Unit, formerly called the North Carolina Cancer Control Program, has been a crucial part of the health care safety net. This program provides funding for cancer diagnosis and treatment for low-income, uninsured residents of North Carolina. The goal of Cancer Assistance Unit staff is to help patients with cancer or suspected cancer and their health care providers navigate the difficult and confusing process of finding resources to pay for cancer care.

History of the North Carolina Cancer Assistance Unit

In 1945, the North Carolina General Assembly created the Cancer Control Program to cover a range of cancer prevention, early detection, diagnostic, and treatment services. In the years since the program was established, cancer prevention and early detection initiatives have been assumed by other programs within the North Carolina Division of Public Health, and the focus of the Cancer Control Program has shifted toward direct payment for diagnostic testing and treatment for low-income, uninsured patients. The program was recently renamed the Cancer Assistance Unit to reflect this change in emphasis.

“The goal of Cancer Assistance Unit staff is to help patients with cancer or suspected cancer and their health care providers navigate the difficult and confusing process of finding resources to pay for cancer care.”

The North Carolina Cancer Control Program was the first program in the nation to provide funds for treatment of low-income, uninsured patients with cancer, and the program still has few peers nationally. Over the last 63 years, the program budget has grown from \$36,700 to \$3,362,048.

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Who Does the North Carolina Cancer Assistance Unit Serve?

Eligibility Criteria

To qualify for services through the Cancer Assistance Unit, patients must meet residency, financial, and medical criteria. Applicants must live in North Carolina and be United States citizens, have a citizenship application in process, have a permanent resident visa or an application for one in process, or be a migrant farm worker. They must have a gross family income at or below 115% of the federal poverty guidelines. In addition, applicants must not have health insurance that covers the service in question.

To be medically eligible for diagnostic services, a patient must have a condition with a high likelihood of being cancer, and the services requested must be medically necessary to confirm or rule out cancer. Diagnostic services for cervical dysplasia or other precancerous conditions are also covered by the program. To be medically eligible for treatment services, the patient must have cancer or a precancerous condition and must have an expected 5-year survival rate of 25% or greater.¹ The treatment services requested must be related to the patient's cancer diagnosis.

We have compiled clinical and demographic data on patients served by the Cancer Assistance Unit from July 2005 until June 2006 in order to better understand who the program serves and whether the program is targeting areas of greatest need. These data are presented in Tables 1-4. The Cancer Assistance Unit has 2 sub-programs which will be considered separately: the Diagnostic Program for patients with suspected cancer and the Treatment Program for patients with a confirmed diagnosis of cancer.

Clinical Characteristics of Program Participants

Cervical dysplasia is by far the most common condition addressed in the Treatment Program, followed by breast cancer, colorectal cancer, and prostate cancer. (See Table 1.) The greatest expenditure for patients enrolled in the Treatment Program is for breast cancer, followed by colorectal cancer, uterine cancer, prostate cancer, and cervical dysplasia. Some conditions have a higher cost of care even though there are fewer patients with these diagnoses enrolled in the program.

The distribution of cancers treated in this program does not reflect the overall distribution of cancers diagnosed in North Carolina. Certain cancers are over- or underrepresented. For example, breast cancer accounts for only 16% of new cancer diagnoses in North Carolina each year but accounts for 29% of

Table 1.
Diagnoses and Expenditures in the Treatment Program, Fiscal Year 2006

Cancer	Patients Served n (%)	Total Dollars Spent	Dollars spent per patient
Cervical dysplasia	239 (39.8)	\$130,539	\$546
Breast	105 (17.5)	\$596,746	\$5,683
Colon and rectum	33 (5.5)	\$344,639	\$10,444
Prostate	27 (4.5)	\$153,078	\$5,670
Carcinoma in situ (breast, genitourinary)	26 (4.3)	\$39,883	\$1,534
Corpus uteri	25 (4.2)	\$234,539	\$9,382
Cervix	18 (3.0)	\$101,788	\$5,655
Non-Hodgkin lymphoma	13 (2.2)	\$76,239	\$5,865
Non-melanoma skin	12 (2.0)	\$20,962	\$1,747
Melanoma	11 (1.8)	\$58,967	\$5,361
Hodgkin lymphoma	11 (1.8)	\$36,595	\$3,327
Ovary	10 (1.7)	\$70,450	\$7,045
Other cancers	91 (15.2)	\$574,716	\$6,316
Total	621	\$2,439,141	\$3,928

Note: Percentages add up to greater than 100% because some patients are diagnosed with more than one cancer. Total number of unique patients with complete diagnostic and financial data is 600.

patients with cancer served by the Cancer Assistance Unit. Lung cancer accounts for 15% of new cancer diagnoses in North Carolina but only for 1% of cancer patients in the program. Patients with prostate cancer are also underrepresented, accounting for 14% of new cancer diagnoses in the state but only for 7% of cancer patients in the program.^a

We hypothesize several reasons for these differences. First, cancers with poorer prognoses, such as lung or pancreatic cancer, are underrepresented because of the eligibility requirement of an expected 5-year survival of 25% or greater. Second, the program has historically been a resource for local public health departments, which serve predominantly young women in their family planning and maternity care programs, for follow-up of patients with abnormal

North Carolina Cancer Assistance Unit Eligibility Criteria at a Glance

- North Carolina resident
- Income ≤115% of the federal poverty guideline
- Diagnosis of cancer or a condition strongly suspicious of cancer (includes precancerous conditions)
- 5-year survival rate of 25% or greater

^a Percentages presented in this paragraph differ from those in Table 1 because patients with cervical dysplasia are excluded. Because cervical dysplasia is not a reportable condition, the number of patients diagnosed with cervical dysplasia in North Carolina is unknown.

screening tests. Other providers in the community might be less aware of the resources that the Cancer Assistance Unit provides.

A similar pattern exists in the clinical characteristics of patients in the Diagnostic Program. (See Table 2.) The vast majority of patients in this program are enrolled for follow-up of abnormal pap smears or cervical dysplasia. The program appears to be less successful reaching patients with abnormal screening tests for other cancers. The highest program expenditures are for cervical, breast, ovary, colorectal, and uterine cancers. Program utilization does not reflect the distribution of cancers in North Carolina. Similar to what was seen with the Treatment Program, the Diagnostic Program disproportionately addresses cervical dysplasia and, to a lesser extent, breast cancer.

Since we do not know how many patients in a given year are suspected to have cancer, we cannot determine how many people are eligible for the Diagnostic Program, but it appears that the program is not reaching everyone in need. For example, we project that approximately 11 000 uninsured women between the ages of 50 to 65 each year in North Carolina have abnormal mammograms and need follow-up testing.^b The actual number of women in this program evaluated for possible breast cancer is far lower.

Demographic Characteristics of Program Participants

The Cancer Assistance Unit disproportionately serves women, probably reflecting the aforementioned historic factors that have led to an emphasis on follow-up of breast and cervical cancer screening. (See Table 3.) A majority of patients have incomes well below 100% of the federal poverty guidelines. Very few patients have any additional health insurance coverage. The racial and ethnic distribution of patients is similar to that of all uninsured patients in North Carolina, except that Hispanic patients are underrepresented, probably reflecting the residency requirements of the program.

Geographic Distribution

Table 4 and Figure 1 (See page 320.) show the geographic distribution of patients served by the Cancer Assistance Unit is different from the geographic distribution of residents in the state. We have used 'patients served per thousand persons living in poverty' as a standardized measure of what proportion of the population in need is being served by this program.

It appears that the program has greater penetration into rural areas than urban areas of the state. For example, a much greater proportion of persons living in poverty are served by the

program in the northeastern and western regions of the state as compared to the central and south central regions. The reason for this discrepancy is unknown. Urban areas of the state may have a greater number of other resources for low-income, uninsured patients. It appears that the program is doing a good job reaching the areas of the state in greatest need, but these figures must be interpreted with caution because of small numbers of patients overall. For example, a single clinic with a large number of referrals could skew the data for an entire region.

Current Challenges

Analysis of the clinical, demographic, and geographic characteristics of program participants demonstrates that the Cancer Assistance Unit is not reaching everyone who could benefit from the program. Certain cancers and geographic regions are underrepresented. However, program administrators have been reluctant to further promote the program because of resource limitations. In most years, funds are completely depleted by serving the program's current participants.

In recent years, the Cancer Assistance Unit has seen an increasing demand for services, fueled by several overall trends in both North Carolina and the nation, to the extent that current program funding is no longer able to keep pace with demand. First, the

Table 2.
Diagnoses and Expenditures in the Diagnostic Program,
Fiscal Year 2006

Suspected Cancer	Patients Served n (%)	Total Dollars Spent	Dollars spent per patient
Cervix*	1536 (80.5)	\$490,660	\$319
Breast	146 (7.7)	\$142,403	\$975
Corpus uteri	55 (2.9)	\$51,858	\$943
Colon and rectum	45 (2.4)	\$75,368	\$1,675
Skin	28 (1.5)	\$14,679	\$524
Vagina	26 (1.4)	\$4,944	\$190
Ovary	22 (1.2)	\$81,095	\$3,686
Urinary tract	21 (1.1)	\$44,751	\$2,131
Head and neck	19 (1.0)	\$42,955	\$2,261
Lung	19 (1.0)	\$31,536	\$1,660
Hematologic	16 (0.8)	\$27,213	\$1,701
Prostate	7 (0.4)	\$5,871	\$839
Other diagnoses	430 (22.5)	\$256,605	\$597
Total	2370	\$1,269,938	\$536

*Includes cervical dysplasia

Note: Percentages add up to greater than 100% because some patients fall into more than one diagnostic category. Total number of unique patients with complete diagnostic and financial data is 1908.

b This figure is based on census estimates of numbers of uninsured individuals and data on positive mammogram rates.

Table 3.
Patient Demographics

	Treatment Program n (%)	Diagnostic Program n (%)
Age		
<20	53 (9)	372 (19.5)
21-34	188 (31)	979 (51.3)
35-44	71 (12)	210 (11.0)
45-54	148 (25)	199 (10.4)
55-64	128 (21)	143 (7.5)
65+	12 (2)	5 (0.3)
Race		
White	402 (67)	1189 (62.3)
African American	161 (27)	608 (31.9)
American Indian	10 (2)	24 (1.3)
Hispanic	7 (1)	39 (2.0)
Asian/Pacific	7 (1)	17 (0.9)
Other	13 (2)	31 (1.6)
Sex		
Male	107 (18)	103 (5.4)
Female	493 (82)	1805 (94.6)
Income		
<85% FPG*	412 (69)	1271 (66.6)
85-100% FPG	98 (16)	321 (16.8)
100-115% FPG	84 (14)	306 (16.0)
>115% FPG	4 (1)	8 (0.4)
Insurance status		
Uninsured	553 (92)	1878 (98.4)
Some insurance	47 (8)	30 (1.6)

*FPG=Federal Poverty Guideline

Figures do not always add up to 100% because of missing data on some patients.

number of individuals living with cancer in the state is increasing due to increased incidence and decreased mortality.^{2,3} In addition, the number of individuals living below the poverty level and without insurance is increasing.^{4,5} These trends translate to a greater number of patients who are eligible for the services of the Cancer Assistance Unit.

At the same time, the cost of medical care has increased, resulting in a higher cost of care for each patient served by the program. In the United States from 1987 to 2000, the cost of cancer care for an individual with cancer increased by 41.9%.⁶ The rate of increase in the cost of cancer care has likely accelerated

in the last several years due to increased use of targeted cancer therapies and advances in diagnostic technologies. While these technological advances have improved outcomes for cancer patients, they have also increased the cost of care.

All of these trends contribute to a rise in the cost of running the Cancer Assistance Unit, but funding for the program has not kept pace with increased cost.

Future Directions

In order to address the challenges of increasing demand while continuing to provide quality services to those in greatest need, the Cancer Assistance Unit is in the process of reconsidering program policies and eligibility criteria. Several strategies have been implemented to prioritize funds toward areas where they can have the greatest impact.

The first change is in the area of cervical dysplasia diagnosis and treatment. Although the cost of care for any individual patient with cervical dysplasia is low, these individuals represent a large proportion of patients served by the program. Changing the way the program handles cervical dysplasia could have a large impact. In the past, decisions about how best to manage cervical dysplasia were left to the treating physician. However, clear practice guidelines exist for management of cervical dysplasia.^{6,7} The Cancer Assistance Unit now requires that physicians present clear justification for their decisions when they apply for reimbursement for services that fall outside these guidelines, even then they are not guaranteed coverage. Although diagnosis and treatment algorithms for most cancers are more complex, the Cancer Assistance Unit might be able to apply this model to other cancers to ensure that limited funds are being used for medical services that meet professional guidelines for quality care.

Second, the program has begun to ask providers to make use of other sources of financial assistance for their patients. Some of the increase in cost of cancer care in recent years is related to pharmaceutical costs. Certain targeted therapies can cost tens of thousands of dollars, which is not a trivial amount for a program with a budget of only \$3.3 million. The companies that produce many of these medications have patient assistance programs which help with the cost for low-income, uninsured patients. By no longer paying for medications that patients could obtain through other resources, the Cancer Assistance Unit can ensure that limited resources go further.

c Consensus guidelines on management of cervical dysplasia have been produced by the American Society for Colposcopy and Cervical Pathology, in cooperation with the American Cancer Society, National Cancer Institute, Society of Gynecologic Oncologists (SGO), American College of Obstetricians and Gynecologists (ACOG), the Centers for Disease Control and Prevention (CDC), and others.

Figure 1.
Regional Distribution of Program Participants



A third change that the program is considering, but has not yet implemented, is limiting coverage to cancers for which screening and early detection improves outcomes. Because program resources are limited, program staff has to make difficult decisions about how to prioritize use of funds. Historically, the Cancer Assistance Unit has provided an important safety net for programs that promote screening and early detection. Screening programs cannot be effective unless there is a mechanism for diagnostic testing and treatment of patients with abnormal screening tests. It is therefore crucial to keep funding for these follow-up services in place, even if there are not adequate resources to provide funding for all low-income, uninsured patients with cancer or suspected cancer.

Finally, the Cancer Assistance Unit is working to become not only a source of direct payment for cancer diagnosis and treatment services but also a clearinghouse of information about financial assistance programs and services available in each county of the state. Cancer patients, families, physicians, and other health professionals will be able to access information on cancer resources through the North Carolina Comprehensive Cancer Program's Web site (www.nccancer.com). With a limited program budget and defined eligibility criteria, this program will never be able to enroll all patients with cancer who have financial needs. But in the future, program staff members hope that the Cancer Assistance Unit can become a single point of contact for patients seeking more information about how to address financial challenges related to cancer care.

The North Carolina Cancer Assistance Unit has a long history of helping some of North Carolina's most vulnerable

Table 4.
Geographic Distribution of Patients Served by Program

Region	Patients Served by Treatment Program (n=600)	Patients Served per 1000 Persons Living in Poverty: Treatment Program*	Patients Served by Diagnostic Program (n=1908)	Patients Served per 1000 Persons Living in Poverty: Diagnostic Program*
Western	71	0.702	286	2.827
North Central	145	0.477	495	1.627
South Central	66	0.304	163	0.750
Central	30	0.157	107	0.559
Southeastern	94	0.483	294	1.511
Northeastern	194	0.899	563	2.608

*Derived from county-level census estimates of number of individuals living in poverty.

residents through the process of diagnosis and treatment of cancer. The program welcomes inquiries from patients, their families, and their health care providers about how this program may be able to help them. Although increasing demand for services and increasing cost of cancer care place stresses on the program's budget, the Cancer Assistance Unit continues to explore new ways of ensuring that high-quality cancer care is financially accessible to low-income, uninsured residents of North Carolina. **NCMJ**

Contact Information: If you have questions regarding the Cancer Assistance Unit or need help with the application process, please contact Janet Dail, program manager, at 919.707.5321, or visit the program's Web site at www.nccancerassist.com.

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“I am one of the few lung cancer survivors because my cancer was diagnosed early. I quit smoking at the age of 25 and developed cancer 26 years later. Now I am an advocate for advanced research funding for lung cancer research and early detection.”

*—Dusty
Lung Cancer*

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**North Carolina
MEDICAL JOURNAL**

Cancer Survivorship

Marci K. Campbell, PhD; Deborah Mayer, PhD, RN, AOCN, FAAN; Amy Abernethy, MD; Suzanne Carroll, RN, MS, AOCN

The good news is that more patients than ever are surviving cancer. The challenge that this brings, however, is in providing resources, services, information, support, and education to meet the needs of cancer survivors, their families, and caregivers.

It is estimated there are approximately 12 million cancer survivors in the United States today.¹ According to groups including the National Cancer Institute, the National Coalition for Cancer Survivorship, and the Lance Armstrong Foundation, an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition. The population of cancer survivors will continue to grow rapidly as our population ages and as advances in early detection and treatment allow more and more pediatric and adult cancer patients to live through and beyond cancer. Currently, more than 65% of adult and 78% of childhood cancer patients survive for at least 5 years beyond initial diagnosis²—but not without a cost. Rather than being seen as a death sentence as in previous generations, cancer is becoming conceptualized more as a chronic disease, especially for cancers such as prostate, breast, and colon where survival rates are quite high for patients when diagnosed in early stages. This chronic disease model of cancer argues for a greater focus on quality of life and health promotion to optimize functioning and prevent additional cancers as well as other chronic diseases for which cancer survivors may be at greater risk, such as diabetes and cardiovascular disease.³

Whereas most of the focus of cancer therapy is, importantly,

on eradicating or controlling the disease and saving lives, many survivors experience an array of enduring physical symptoms which may develop or persist for years after the completion of active cancer treatment.⁴ Not only can the disease itself cause lasting damage, but the side effects of treatment approaches—primarily chemotherapy, radiation therapy, surgery, and hormone therapy—can permanently damage various organ systems and can cause long-term functional impairment.^{5,6} Although there

“...patients described the experience as feeling they were ‘dropped off a cliff’ and that rather than a time of celebration, the end of active treatment can be the most frightening time since the initial diagnosis.”

is substantial variation according to factors such as type and stage of cancer, type of treatment, and demographics such as age, survivors commonly experience problems such as fatigue, pain, neuropathies, and lymphedema. In addition, a growing body of evidence underscores the psychosocial impact of cancer on patients during both active treatment and subsequent survivorship. Psychosocial issues related to cancer include anxiety, depression, and fear of recurrence, which can lead to clinically significant problems in many cancer survivors and their families.⁷ The recent Institute of Medicine of the National Academies report, *Cancer Care for the Whole Patient: Meeting Psychosocial*

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Health Needs, has drawn widespread public and professional attention to this critical aspect of cancer care, but as yet the psychosocial needs of most cancer survivors are inadequately addressed.⁸

In 2006, the Institute of Medicine and National Research Council (IOM/NRC) issued the report *From Cancer Patient to Cancer Survivor: Lost in Transition*.⁵ This landmark report highlighted many of the problems that cancer patients face once initial treatment is completed. In particular, the report documented a problem with a lack of continuity of care and follow-up between the hospital/specialists that have provided the initial cancer treatment and the patient's subsequent return to the community health care provider. In the report, patients described the experience as feeling they were "dropped off a cliff" and that rather than a time of celebration, the end of active treatment can be the most frightening time since the initial diagnosis. Many patients report that once active treatment is over they feel they are no longer combating the illness, and they may experience a loss of support from the treatment team combined with ever-present uncertainty about cancer recurrence. In addition, survivors may face issues such as economic and employment problems, difficulties with medical expenses and health insurance, and adjusting to the "new normal" of living with and beyond cancer.

One of the key recommendations of the 2006 IOM/NRC report was to provide each patient with a treatment summary and a survivor care plan that includes recommendations for follow-up care and surveillance as well as for preventive behaviors such as smoking cessation, physical activity, and weight management. The treatment summary document serves as information and education for the patient as well as a way to transmit this information and recommendations to the primary care provider or whomever will be following up with the patient for primary health care. Currently several groups including the American Society of Clinical Oncology, the American Cancer Society, and the Lance Armstrong Foundation are actively developing templates and software to produce treatment summaries. It is anticipated that this will become a standard of care for all cancer survivors in the near future. In addition, patients and clinicians can utilize resources such as Oncolink/Oncolife from the University of Pennsylvania's Abramson Cancer Center (www.oncolink.org/oncolife) to generate survivorship care plans. Given the unique health information and support needs and interests of each patient, however, such care plans should be further tailored to the individual by the health care team. The National Cancer Institute also has a 'Facing Forward' series addressing some of these issues for patients and caregivers that is helpful during the transition from treatment to extended survival.

In North Carolina, cancer survivorship has emerged in recent years as a major focus of attention. The North Carolina Advisory Committee on Cancer Coordination and Control (A4C) has included survivorship in the State Cancer Plan and recently established a Survivorship Workgroup composed of key state officials, community advocates, cancer survivors, and researchers. The A4C, led by Walter L. Shepherd and supported

"Unstoppable is the best word to describe me. I was just 28 years old when diagnosed with stage I cervical cancer. After the surprise, crying and getting mad, I realized that I had to be strong not only for me but for my mother. Cancer gave me an opportunity to share my story with others. To realize what was truly important in life, family. So, 11 years later I am still unstoppable, doing volunteer work, raising awareness, and keeping active. Life does go on. I always say, surviving is the first step—living is what matters."

"Imparable, es la palabra que mejor describe a Marie. Solo tenía 28 años de edad cuando fui diagnosticada con etapa I de cáncer cervical. Luego de la sorpresa, los llantos y de darme coraje llegue a la realización que tenía que ser fuerte, no solo por mí sino por mi madre también. El haber tenido cáncer me dio la oportunidad de compartir mi historia con otros y ayudarlos. Me ayudo a reconocer lo que realmente era importante en esta vida, la familia. Así que, 11 años después sigo imparabile, realizando trabajo voluntario, llevando el mensaje que es cáncer a nuestra comunidad y manteniéndome activa. La vida continúa. Siempre digo, sobrevivir es el primer paso—vivir es lo que importa."

**— Marie
Cervical Cancer**

by legislative funding, has convened 2 highly successful statewide Survivorship Summits in June 2007 (Research Triangle Park) and June 2008 (Winston-Salem) that have focused on identifying and addressing the needs of cancer survivors.

North Carolina is fortunate to have 3 National Cancer Institute-designated Comprehensive Cancer Centers at Duke University, the University of North Carolina at Chapel Hill,

and Wake Forest University. Each Cancer Center is addressing survivorship needs with innovative programs and services. In January 2008, the University of North Carolina at Chapel Hill's Lineberger Comprehensive Cancer Center was awarded a prestigious Lance Armstrong Foundation (LAF) Center of Excellence in Cancer Survivorship. This Center, also supported by funds from the V Foundation, is 1 of 8 in the United States—and the only Center in the southeast—to have this designation. The mission of the UNC Lineberger Survivorship Center is to promote optimal health and well-being for cancer survivors by promoting outstanding clinical services, education, community outreach, and research. The approach is for every cancer patient to receive a Treatment Summary and Survivorship Care Plan at the end of active treatment, with appropriate follow-up and surveillance for their primary cancer and other risk factors, effective management of symptoms such as fatigue and pain, psychosocial support for the patient and family/caregivers, and health promotion advice and resources in order to ensure the best possible long-term quality of life.

Programs at Duke University Medical Center also reflect current practices with respect to survivorship care. The Duke Center for Cancer Survivorship (DCCS) was founded to broaden awareness of the diverse needs of patients, family members, and caregivers as they navigate the cancer journey, while providing an array of resources designed to help patients live fuller lives throughout treatment and survivorship. A multidisciplinary team of health care providers collaborates to provide family and individual counseling, support groups, self-image resources, multimedia patient education materials, physical and occupational therapy, and pharmaceutical and nutritional counseling. Recently the DCCS opened Duke's first long-term survivorship clinic for breast cancer survivors. The primary goal of this clinic is to empower patients to make healthy lifestyle choices that contribute to improved quality of life and to minimize the risks of secondary cancers and other illnesses.

Wake Forest University's Comprehensive Cancer Center addresses survivorship issues through their psychosocial oncology service, the Cancer Patient Support Program (CPSP). This program provides psychosocial support and counseling services that are integrated into the medical care of patients and extend

into survivorship. The program strives to enhance the quality of life of patients and family members during diagnosis, treatment, and survivorship. In addition to individual counseling, the program offers educational and appearance resources as well as referrals to community support and advocacy groups.

Recognizing the priority of cancer survivorship issues, Wake Forest is currently developing a survivorship program which will address long-term survivor issues including careful evaluation and check-ups, assessment for treatment-related problems, health promotion and health maintenance, and the psychosocial aspects of cancer survivorship.

In 2007, funds from the NC General Assembly established the University Cancer Research Fund (UCRF), a \$50 million annual appropriation to support cancer care and research. A major priority of this UCRF funding is to promote cancer survivorship research and the reduction of cancer health disparities across our state. The UNC Lineberger Comprehensive Cancer Center has spearheaded the establishment of a North Carolina Cancer Outreach Network with the goal of collaborating with communities, oncology centers, and hospitals in order to provide survivorship clinical care and education. In addition, the UCRF funds will support a landmark research cohort study that will follow cancer patients from initial diagnosis and treatment through long-term survivorship in order to better understand how to promote the health and well-being of this important population.

We are in the midst of an exciting time for cancer survivorship in North Carolina. Across the state there is evidence of growing interest, momentum, and commitment of resources to provide appropriate programs and services for cancer survivors and those who care for them. However we still have a way to go in terms of finding and disseminating optimum models for survivorship care and education as well as reaching survivors in all communities, especially those in rural areas, minorities, and the medically underserved. Research is urgently needed to better understand the needs of cancer survivors and to design and evaluate effective programs and interventions to meet these needs.⁹ Progress will require ongoing dedication and support from researchers, practitioners, patients, agencies, advocacy groups, legislators, and others working together to achieve these goals. **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>*

Cancer Incidence and Mortality Trends in North Carolina

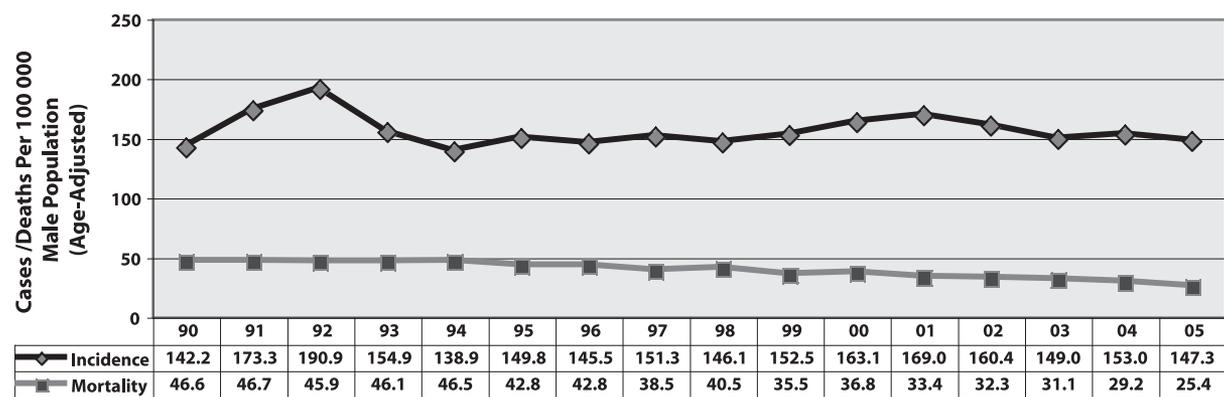
Cancer incidence (new case) and mortality rates change over time as screening tests are implemented, more effective treatments discovered, and risk factors emerge or decline. Trends in both incidence and mortality can provide insight into changes in these factors. The portrayal of disparities and trends by subgroups of the population helps in targeting scarce resources for planning and evaluation of prevention, screening, and treatment programs.

We calculated annual cancer incidence and mortality rates (age-adjusted to the 2000 United States standard population) from 1990 through 2005, the most recent complete year of cancer incidence data available. Trends are presented for the 4 most frequently diagnosed cancers - lung and bronchus, colon and rectum, prostate, and female breast - by white and African American race and by gender. Breast cancer incidence includes in situ cancers. For breast and prostate cancer rates, female and male populations, respectively, are used in the denominators. Therefore, these sex-specific rates are not directly comparable to the other rates in magnitude.

Prostate Cancer

A sharp peak in prostate cancer incidence in the early 1990s was likely due to increased Prostate Specific Antigen (PSA) testing.¹ (See Figure 1.) Otherwise, prostate cancer incidence rates have been steady. There has been a significant decrease in prostate cancer mortality since the early 1990s (46.6 deaths per 100 000 male population in 1990 to 25.4 in 2005). (See Figure 1.) The disparity between African American and white male

Figure 1.
North Carolina Prostate Cancer Incidence and Mortality Rates (1990-2005)



incidence rates is large, and the disparity has increased since 1991 (from a rate ratio of 1.21 in 1991 to 1.72 in 2005). (See Figure 2.) The mortality rates for both white and African American men have declined since the early 1990s, and the disparity has increased slightly (from a rate ratio of 2.45 in 1991 to 2.61 in 2005). (See Figure 3.)

Figure 2.
North Carolina Prostate Cancer Incidence Rates By Race (1990-2005)

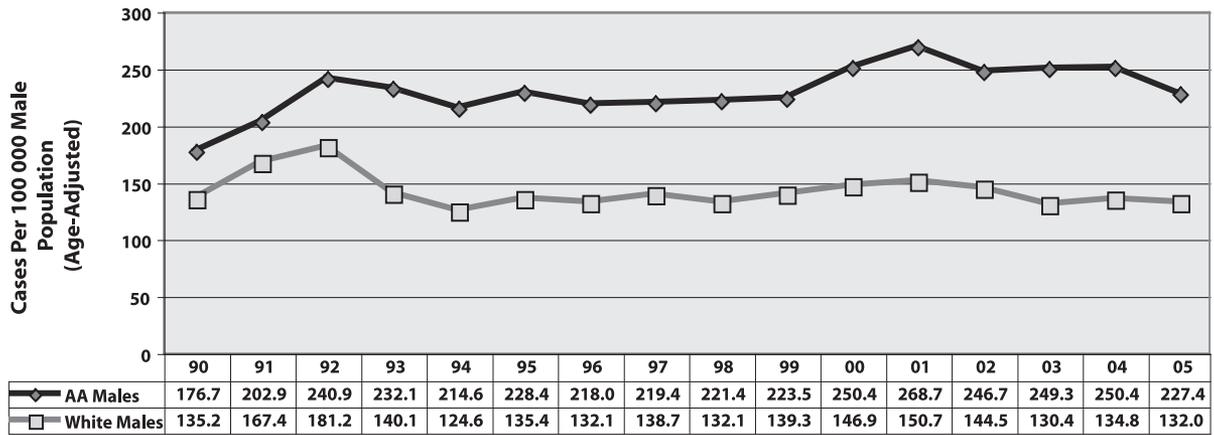
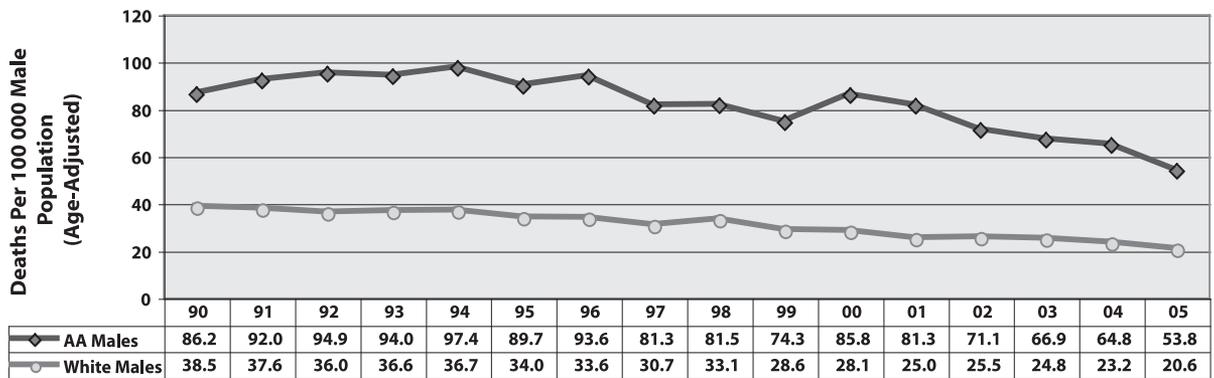


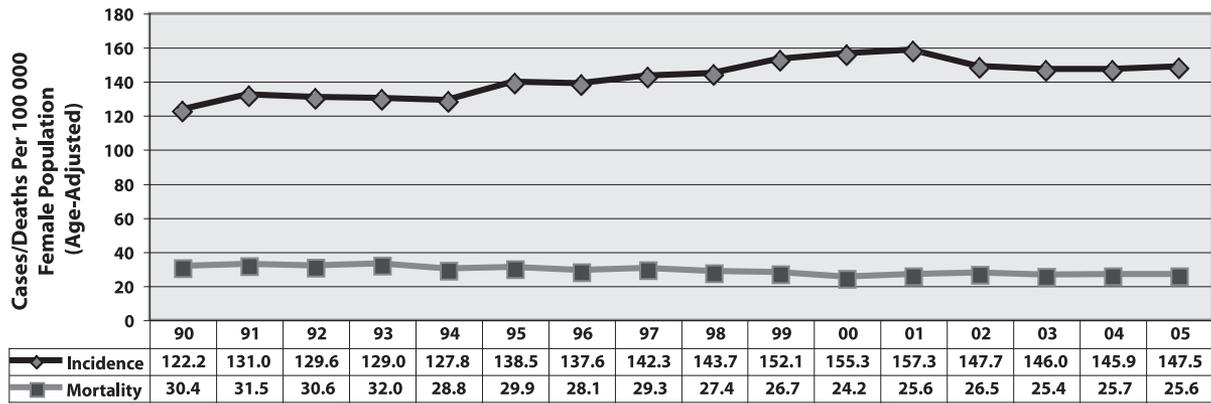
Figure 3.
North Carolina Prostate Cancer Mortality Rates By Race (1990-2005)



Female Breast Cancer

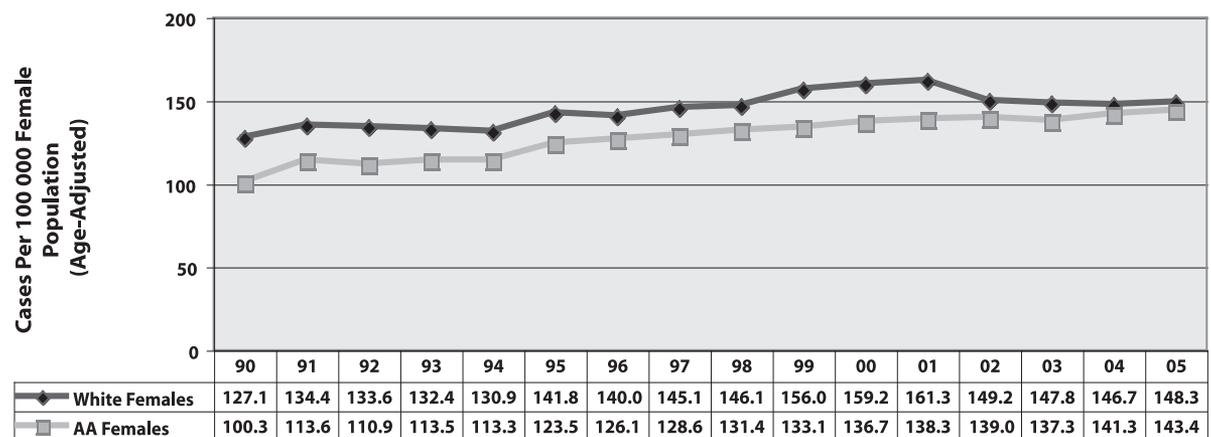
There was a steady increase in female breast cancer incidence from 1990 through 2001, but rates have decreased since 2001. This is consistent with trends in the United States.² (See Figure 4.) This steady increase in incidence occurred for both whites and African Americans until 2001, with a decrease among white women

Figure 4.
North Carolina Female Breast Cancer Incidence and Mortality Rates (1990-2005)



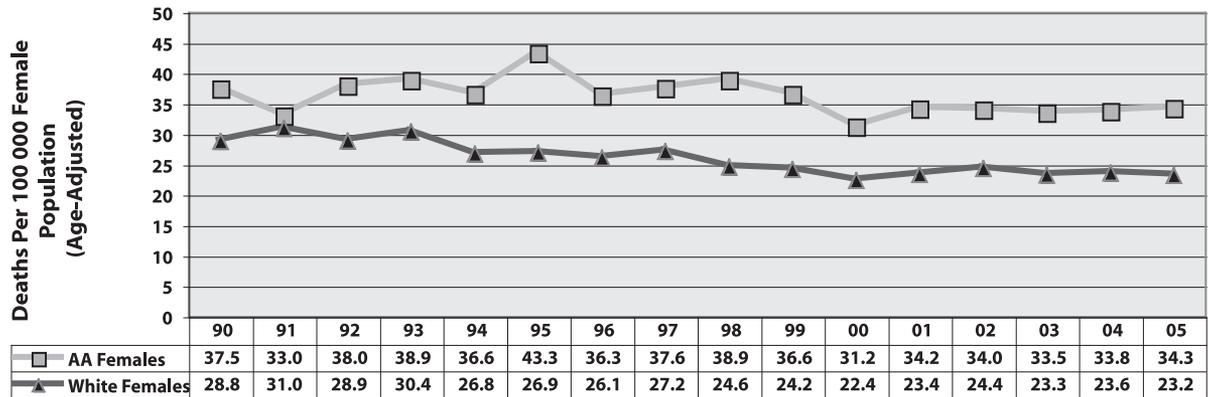
in 2002 followed by stability through 2005. (See Figure 5.) The trend for white women is consistent with that in the United States.² While the breast cancer incidence rate for African American women has also decreased recently in the United States, African American rates continue to increase in North Carolina. (See Figure 5.)

Figure 5.
North Carolina Female Breast Cancer Incidence Rates By Race (1990-2005)



Likely due to early detection, the North Carolina breast cancer mortality rate decreased from 30.4 per 100 000 in 1990 to 25.6 per 100000 in 2005. (See Figure 4.) This decrease occurred for both African American and white women from 1990 through 2000, but rates have remained steady since 2001. (See Figure 6.)

Figure 6.
North Carolina Female Breast Cancer Mortality Rates By Race (1990-2005)



Lung Cancer

Unlike some other cancers, the mortality rates for lung cancer are only moderately lower than the incidence rates. (See Figure 7.) Lung cancer incidence and mortality rates are consistently greater for males than for females. The disparity between males and females for incidence and mortality has decreased since 1990 due to a decrease in male mortality and increases in female incidence and mortality. (See Figure 8.)

Figure 7.
North Carolina Lung/Bronchus Cancer Incidence and Mortality Rates (1990-2005)

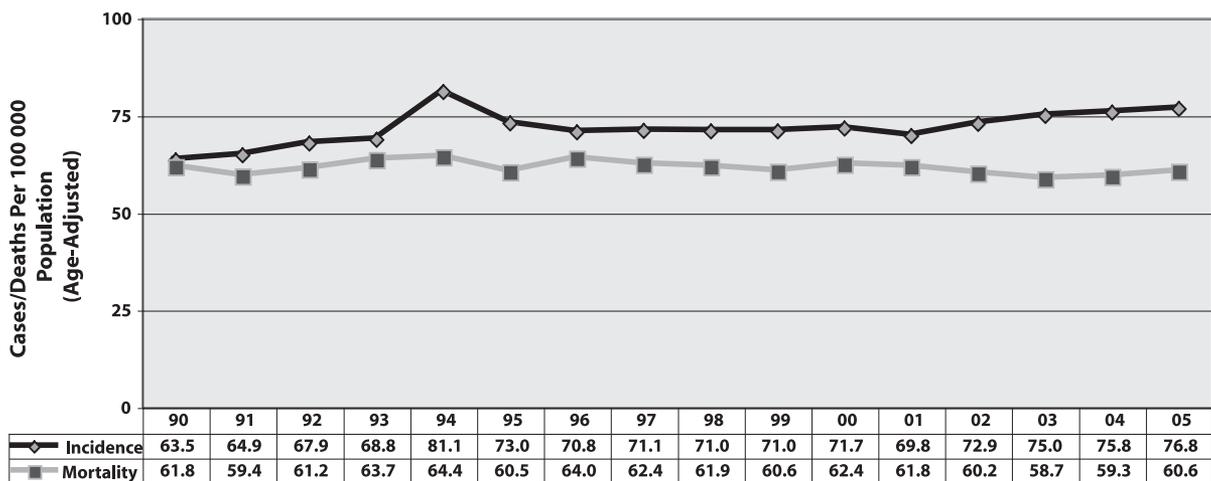
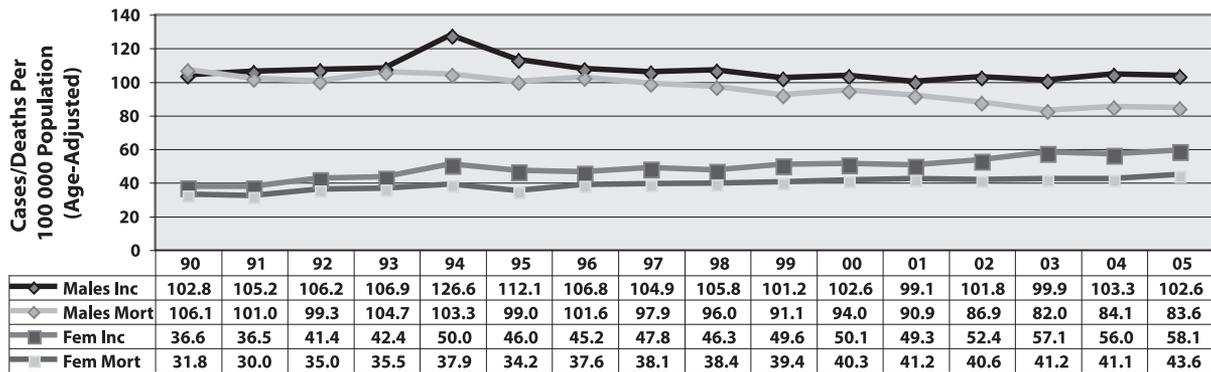


Figure 8.
North Carolina Lung/Bronchus Cancer Incidence and Mortality Rates By Gender (1990-2005)



Lung cancer incidence rates among African American and white males have been steady, but higher than the rates for females. (See Figure 9.) Female incidence and mortality have increased for both African Americans and whites, with consistently higher incidence and mortality rates among white women. (See Figures 9 and 10.)

Since 1990, African American and white male lung cancer mortality rates have decreased, as has the disparity between African American and white males. (See Figure 10.)

Lung cancer has the highest mortality rates of all cancer sites, and because of the increase in female mortality (see Figure 8), the overall rates have not improved over time. (See Figure 7).

Figure 9.
North Carolina Lung/Bronchus Cancer Incidence Rates By Race and Gender (1990-2005)

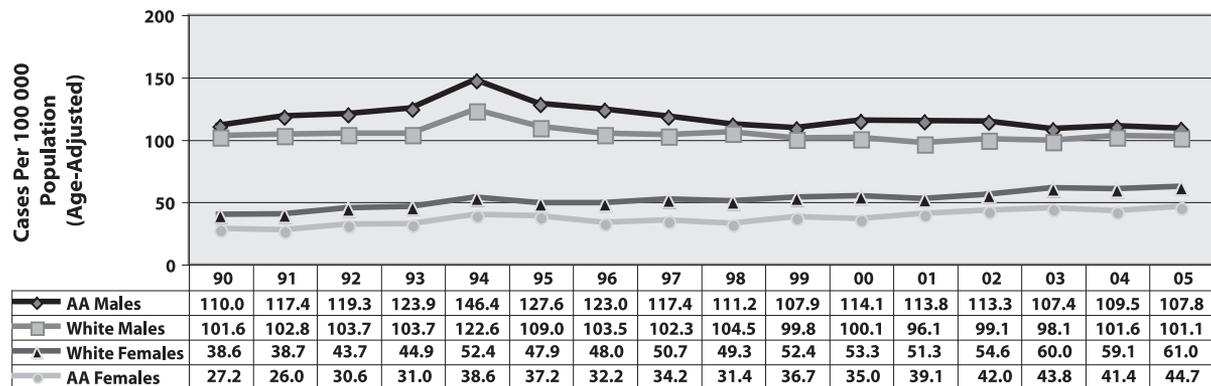
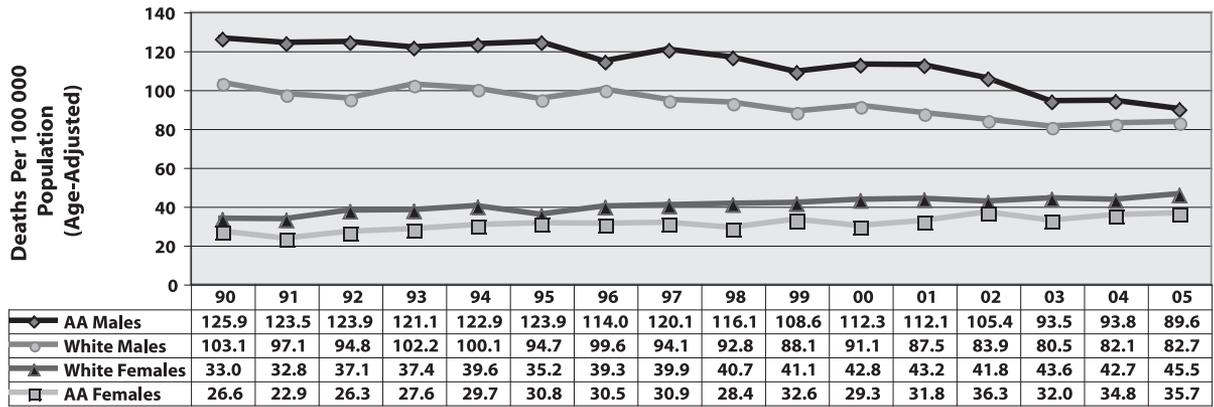


Figure 10.
North Carolina Lung/Bronchus Mortality Rates By Race and Gender (1990-2005)



Colon/Rectum Cancer

Colon/rectum cancer incidence has remained steady over time, but mortality has decreased. (See Figure 11.)
 Colon/rectum cancer incidence and mortality rates are consistently higher for males than for females, and the mortality rates for both males and females have decreased over time. (See Figure 12.)

Figure 11.
North Carolina Colon/Rectum Cancer Incidence and Mortality Rates (1990-2005)

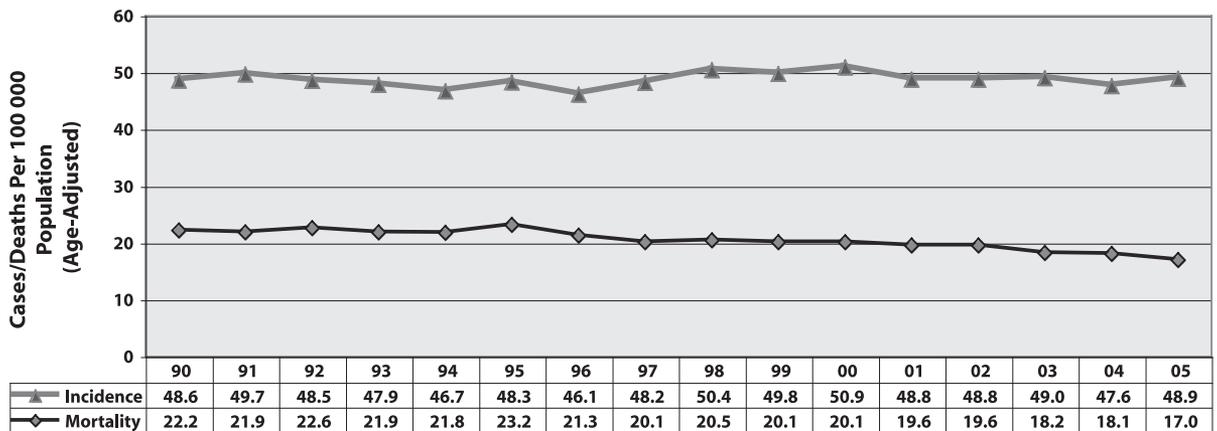
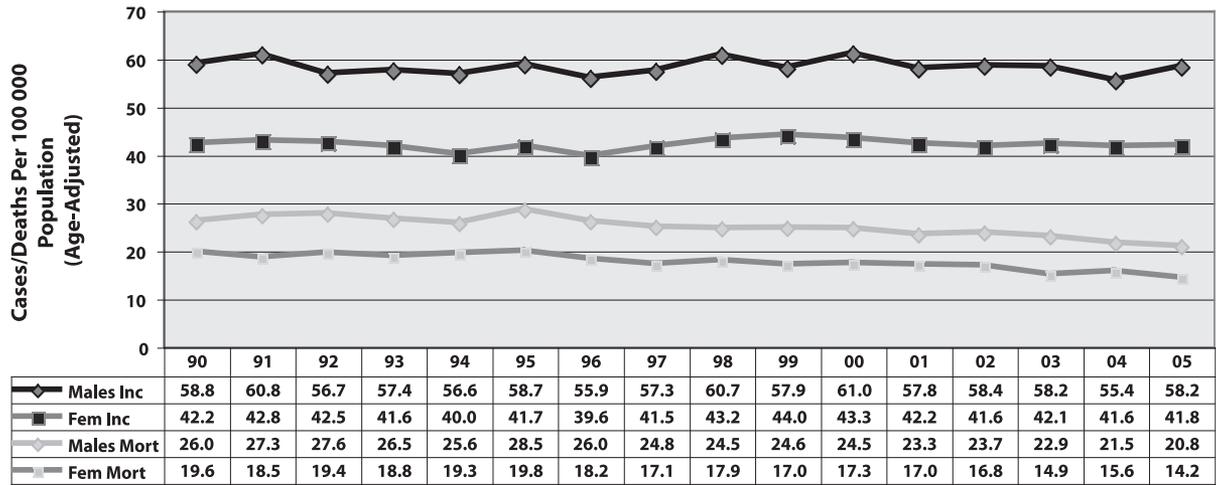


Figure 12.
North Carolina Colon/Rectum Cancer Incidence and Mortality Rates By Gender (1990-2005)



Colon/rectum cancer incidence rates are higher for both African American males and females compared to white males and females. From 2002-2005, the African American/white male disparity has decreased. (See Figure 13.)

Colon/rectum mortality rates have decreased for white males and females and for African American females, but not for African American males. (See Figure 14.)

Figure 13.
North Carolina Colon/Rectum Cancer Incidence Rates By Race and Gender (1990-2005)

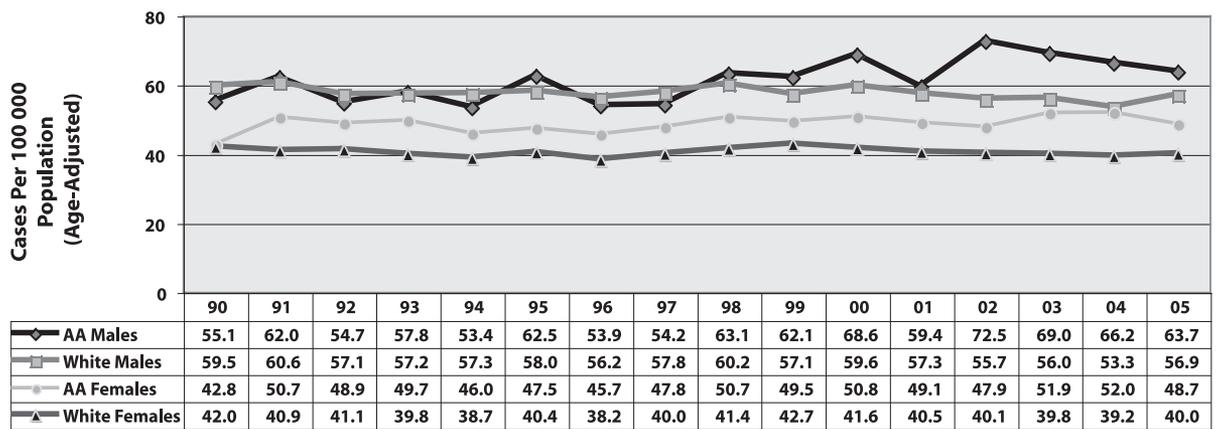
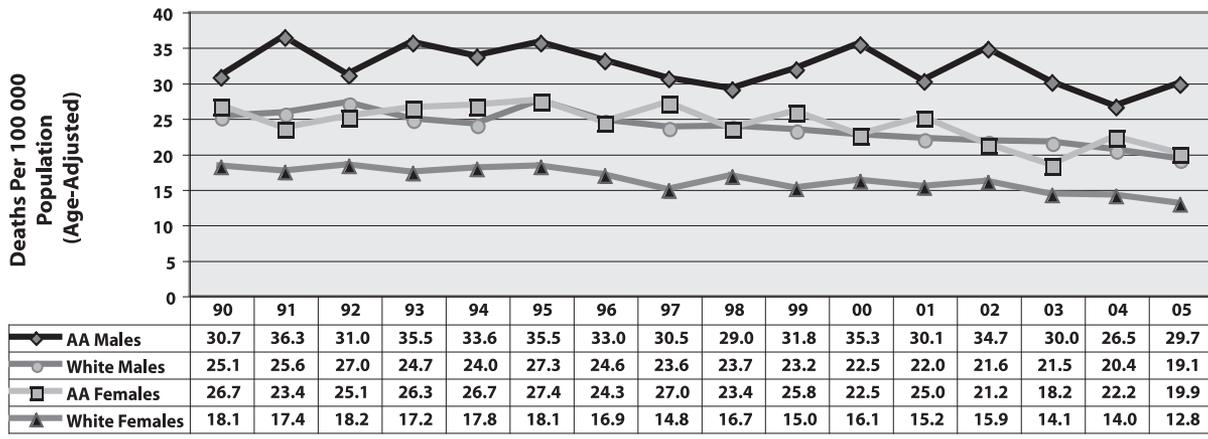


Figure 14.
North Carolina Colon/Rectum Mortality Rates By Race and Gender (1990-2005)



Conclusion

Overall, decreasing trends in cancer incidence and mortality demonstrate progress in prevention, early detection and treatment for prostate, breast, and colorectal cancers. The notable exception is increasing lung cancer mortality, due to increases in both incidence and mortality among women. For these 4 cancer sites, trends by race and gender reveal disparities that can direct cancer control programs to groups with the most need.

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*Contributed by Chandrika Rao and Karen Knight
 Central Cancer Registry, State Center for Health Statistics, North Carolina Division of Public Health*



Finally!

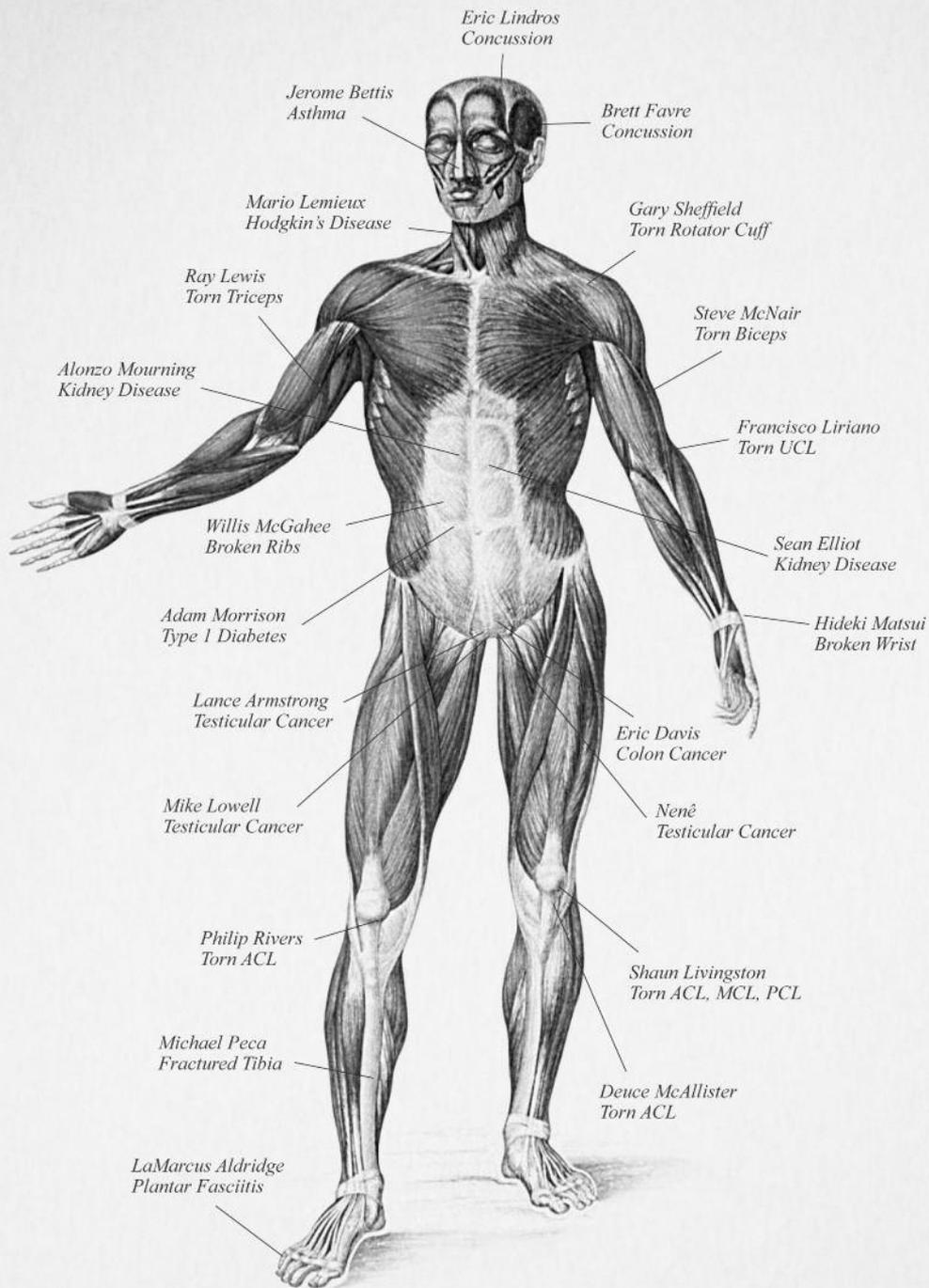
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Using Master Settlement Agreement Dollars to Fund a Statewide Tobacco Cessation Quitline

Vandana Shah; Laura McCormick

The North Carolina Health and Wellness Trust Fund Commission (HWTF) was established by the North Carolina General Assembly in May 2000 to receive 25% of the state's share of the Tobacco Master Settlement Agreement in order to address the health needs of vulnerable and underserved populations. HWTF addresses its statutory mission by investing in programs and establishing partnerships that address critical health needs in 4 major areas: tobacco use among youth, obesity, health disparities, and access to medications. Governed by an 18-member commission of health care experts drawn from a variety of professions, the Health and Wellness Trust Fund has embarked on these 4 major initiatives, all designed to reduce the economic and human suffering from preventable diseases.

The Health and Wellness Trust Fund has awarded over 250 grants to date that build capacity in local communities to prevent and treat chronic health issues. These local grantees make up the infrastructure that has enabled each of the Health and Wellness Trust Fund's preventive initiatives to reach its overall goals. To enhance the impact of local grant infrastructure and to have a more sustainable impact statewide, HWTF also designs and implements mass media campaigns and works to affect policy change at the local and state level. University research and other expert agencies are engaged on an ongoing basis to measure and optimize the effectiveness of all these strategies.

Teen Tobacco Use Rates Have Reached Historic Lows with HWTF Efforts

Tobacco use is the number one avoidable cause of illness and death in the United States, accounting for more than 435 000 deaths each year.¹ It is also the leading cause of preventable death in North Carolina. Through its efforts over the last 5 years, the Health and Wellness Trust Fund has made significant strides in reducing the rate of teen tobacco use in North Carolina. HWTF's Youth Tobacco Use Prevention and Cessation Initiative has resulted in North Carolina's youth smoking rates reaching the lowest point ever recorded in the state's history: middle school smoking has dropped by 51.6%

to a current rate of 4.5%, and high school smoking has dropped by 30.4% to a current rate of 19%. This data translates into 34 000 fewer teen smokers in the state since 2003.² Furthermore, by fall 2008, all 115 school districts in North Carolina will be 100% tobacco free. Only 14 school districts had adopted the policy when HWTF efforts began.

Young Adult Smoking Rates Continue to be High

In spite of the progress in youth smoking rates, young adults (ages 18-24) continue to have the highest smoking prevalence of any age group in North Carolina, a fact which is also true of the rest of the nation. While the current smoking rate for all adults is 22.6%, the young adult rate is 28.2%.³ Grants awarded through HWTF's Tobacco-Free Colleges program will work to replicate the gains in youth tobacco use reduction by discouraging initiation of tobacco use and promoting cessation among our state's young adults.

Why Quitline?

Quitting tobacco is the single most important thing an individual can do to prolong his or her life. And while studies show that most tobacco users want to quit, many are unable to overcome the addiction on their own. Quitlines are telephone-based cessation services that help tobacco users quit through a variety of services including individual counseling, information, and self-help materials. Their effectiveness is well-established. In fact, studies have shown that using a quitline doubles a smoker's chances of successfully quitting as compared to other self-help methods.⁴ Advantages of quitlines as a cessation strategy include accessibility, centralization of care and resources, and cost-effectiveness. In addition, quitlines can contribute to eliminating tobacco-related disparities among some difficult to reach populations by providing tailored services and a degree of anonymity to callers. Quitlines can also provide multilingual services that may be unavailable or unfeasible at the community level.

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Laura McCormick is the director of evaluation and development at the North Carolina Health and Wellness Trust Fund.

Launching QuitlineNC

The Health and Wellness Trust Fund worked with the North Carolina Department of Health and Human Services (DHHS) Tobacco Prevention and Control Branch and with other partners to launch the state's first ever tobacco use quitline in November 2005. QuitlineNC (1-800-QUIT-NOW) provides proactive cessation information and support in English, Spanish, and a multitude of other languages. The service is delivered by trained 'quit coaches' who provide up to 4 callbacks to quitline users to check on progress and to provide additional guidance. Callers may request information about quitting for themselves, a friend, or a family member. QuitlineNC services are available free-of-charge, 7 days a week from 8:00 am until midnight. HWTF funds QuitlineNC services to assist teens and young adults to quit tobacco use as well as to the primary caregivers of those under 18 and teachers in public and private schools statewide. HWTF has allocated nearly \$2 million annually for promoting QuitlineNC and for providing services.

Promoting QuitlineNC to Young Adults Results in Tremendous Increase in Use of Service

In fall 2007, HWTF launched the mass media campaign *Call it Quits* to promote the Quitline to young adults through television, radio, social networking sites, and a Web site (www.quitlinenc.com). This campaign was based on formative research specifically conducted for this demographic by the University of North Carolina at Chapel Hill School of Public Health. During the 4 months that the campaign was running, 745 young adult smokers registered for the free phone service to create their own plan for quitting tobacco. This represents a monthly average of 186 young adult registrants compared to a monthly average of only 34 during the 6 months preceding the campaign—nearly a 6-fold increase in registrations from 18- to 24-year olds.

HWTF Encourages Health Care Providers to Reach Out to Tobacco Users

Strong evidence indicates that physicians increase their patients' smoking cessation rates by routinely identifying smoking status and providing smokers with advice, assistance, and referrals to help them quit. The recently released Clinical Practice Guidelines for Treating Tobacco Use and Dependence⁵ strongly recommends

that clinicians integrate tobacco use screening and assistance into their health care practice. Providers have a significant impact on a patient's tobacco use. Although clinicians may not be able to provide extended counseling in the office setting, they can refer patients to counseling support through the quitline. Research indicates that physician referral to smoking cessation counseling, such as a quitline, is associated with a significantly higher participation rate than simply telling patients they should quit smoking.

In the spring of 2008, HWTF focused its outreach on a statewide effort to educate health care providers about QuitlineNC and began encouraging them to utilize the innovative fax-referral service. The fax-referral service allows health care providers and HWTF's local tobacco grantees to fax an interested tobacco user's contact information directly to the QuitlineNC, where an expert 'quit coach' will make the initial contact with the tobacco user. Once this connection has been made, the tobacco user will receive information and support services. Through partnership with professional societies and organizations, over 10 000 North Carolina physicians were provided with:

- An "Ask, Assist, Refer" help card with scripted prompts for physicians to use in working with patients who smoke.
- A "prescription pad" urging smokers to call QuitlineNC for help in quitting.
- A fax referral pad for health care providers to make initial QuitlineNC contacts.

Since its inception over 2 years ago, QuitlineNC has served over 12 000 North Carolinians. The Centers for Disease Control and Prevention recommended goal for a state tobacco use quitline is at least 2% of the total state population annually, which would be over 177 000 callers (30 times the current number of callers on an annual basis). HWTF and DHHS would like to offer QuitlineNC services to a much larger pool of North Carolina residents that are ready to quit using tobacco but have been limited by funding constraints.

Two million people in North Carolina are still smoking.³ As long as this is the case, HWTF will continue towards its goal of institutionalizing the Quitline as a frontline tobacco cessation resource in our state. By providing ongoing funding for services and promotion, trying to secure additional funding, creating sustainable partnerships with the health care system for referrals, and targeting programming to reach high-risk populations, HWTF's ultimate goal is to reduce tobacco use among all North Carolinians.

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Spotlight on the Safety Net

*A Community Collaboration
David K. Jones*

Promoting Cancer Prevention Through Beauty Salons and Barbershops

The burden of cancer is greater for some population groups than others. African Americans have significantly lower life-expectancies than whites (69.8 years versus 75.7 among men, 76.5 years versus 80.8 among women), as well as the highest death rate and shortest survival rate in the United States for most cancers.¹ Because African American participation in traditional health promotion activities is lower than for other groups,² programs must be adapted or created that work for this segment of the population. Dr Laura Linnan, associate professor of health behavior and health education at the University of North Carolina at Chapel Hill School of Public Health and a member of the Lineberger Comprehensive Cancer Center, is leading the North Carolina BEAUTY and Health Project which seeks to use the social networks within North Carolina beauty salons to spread information to African American women about cancer prevention, detection, and treatment, as well as the importance of a healthy lifestyle. She has also been funded to conduct the Trimming Risk in Men (TRIM) research study to do the same for African American men through barbershops.

These programs have many advantages over general media campaigns in that information is shared from trusted peers (licensed stylists and barbers) and people come in contact with the preventive messages regularly during each salon visit, and for long periods of time while customers receive hair care services. Ironically, Philip Morris USA recognized the potential of this approach to market cigarettes in the 1980s as they considered paying stylists to promote Virginia Slims.³

NC BEAUTY and Health Project

Begun in 2000, the NC BEAUTY and Health Project (Bringing Education and Understanding to You) was based on research describing beauty salons as an important source of social interactions for African American women.⁴ According to Dr Linnan, salons are a particularly good site for health promotion for 4 reasons: reach, frequency of contact, duration of contact, and type of contact. For example, there are over 60 000 licensed stylists working in more than 11 000 salons in North Carolina,⁵ each serving as many as 155 clients per week.⁶ Dr Linnan's data suggests that women visit salons at least once every 8 weeks, with 17% making weekly visits.⁷ Unlike a visit to a doctor's office or clinic which can be very brief, women typically spend 2.5 to 3 hours per visit at each salon visit, depending upon the hair care services they receive. Observational studies have shown that approximately one-fifth (18%) of the conversations during this time are about health topics and 94% of licensed cosmetologists report regularly talking about health issues with their clients.⁷

To begin this work, Dr Linnan first created an advisory board of stakeholders, which included licensed cosmetologists, beauty school directors, a beauty product distributor, local health department representatives, community residents, and health professionals from the Cancer Information Service and the American Cancer Society. Since its creation, the BEAUTY advisory board has played an active role in guiding the development of the program, including stressing the importance of receiving support from local stylists.⁵ To do this, Dr Linnan's team surveyed stylists to find out whether they would be willing to participate, how they thought the program should operate, and what subjects they would feel comfortable talking about with their clients.⁷

Based on the results of this survey, a 7-week pilot study was conducted in 2 beauty salons. Stylists from these salons were trained on basic cancer prevention messages such as eating at least 5 fruits or vegetables per day, doing at least 30 minutes of physical activity per day, and calling the National Cancer Institute's 1-800-4-CANCER toll free phone number for cancer information. Each salon also received educational display materials which included a photo of the cosmetologists and an invitation for customers to "ask your cosmetologist for more information." The reaction from stylists was very positive, as most reported being "completely confident" about incorporating cancer prevention messages into their usual conversations.⁷

During the pilot study, almost all of the salon customers noticed the displays (98% of African American women, 96% of white women) and reported talking to their cosmetologist about the BEAUTY project during their visit (83% of African American women, 89% of white women). After 12 months, close to half (40%) reported having health-related conversations with their cosmetologist at “many” or “almost every” appointment, and a large number of customers remembered ever talking about maintaining a healthy weight (79%), getting 30 minutes of physical activity per day (73%), eating 5 fruits or vegetables per day (68%), not smoking (64%), and the NCI hotline (48%).⁷

After the success of the pilot program, Dr Linnan’s team worked with the advisory board to design a randomized trial of 40 salons used primarily by African American women. Ten salons acted as a control, displaying materials featuring health topics other than cancer, including foot care, stress management, or back injury prevention. To determine which type of cancer intervention would work best, 10 salons received cancer displays plus stylist training workshops, 10 received displays plus health magazines sent to their customers’ homes, and 10 received all 3. The intervention lasted 2 years, after which customers completed questionnaires describing fruit and vegetable intake, level of physical activity, level of fat in their diet, and whether they had gone for cancer screenings.⁵ Data from this trial are being analyzed and will soon be published.

TRIM

Dr Linnan’s team is also working to create a similar program targeting African American men in North Carolina. TRIM (Trimming Risk in Men) is designed to use barbershops as a source of information to help men make informed decisions about prostate and colorectal cancer screening.⁷ A 2-year pilot study trained a cohort of barbers as peer educators. As with beauty salons, interest in developing barbershop-based interventions has grown because of the potential reach and the frequency of contact men have with the intervention in these settings. Dr Linnan’s pilot data reveal that an average of 65 regular customers visit participating shops each week, of which 80% returned at least once every 3 weeks, and 85% reported trying to see the same barber each time. Although barbers initially reported that conversations about health are not typical, they felt very comfortable with the idea of bringing up health topics.⁸ Data from the pilot study are still being analyzed and will be published shortly.

If results from these studies are consistent with the initial BEAUTY pilot program, then this creative approach will serve as an effective model of sharing information on healthy lifestyles to large numbers of typically underserved populations in North Carolina. As Dr Linnan put it, “We know barbers and stylists are willing to promote health messages, and that customers are interested in receiving health information in these settings. Our research is focused on figuring out the right intervention methods and the right intensity of the intervention to produce the kind of changes we think are possible to promote health in these settings – that is an exciting challenge we are eager to pursue with our wonderful community collaborators.”⁹

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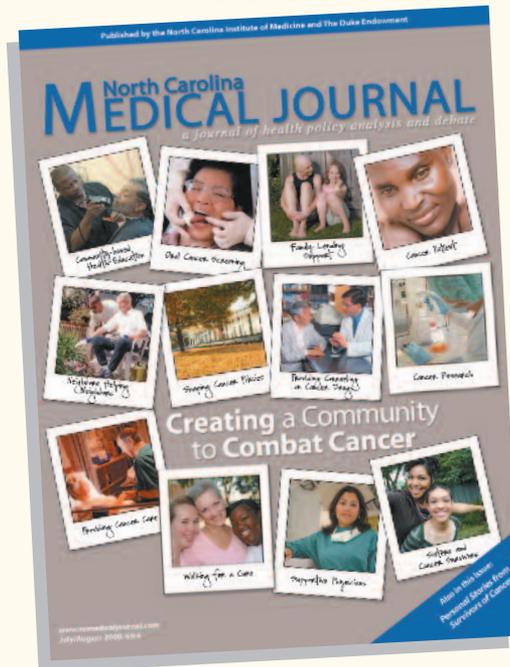
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