Head and Neck Cancer Disparity in Underserved Communities: Probable Causes and the Ethics Involved

Charles E. Moore
Rueben Warren
Sandy D. Maclin Jr.

Journal of Health Care for the Poor and Underserved, Volume 23, Number 4, November 2012, Supplement, pp. 88-103 (Article)

Published by The Johns Hopkins University Press
DOI: 10.1353/hpu.2012.0165

For additional information about this article
http://muse.jhu.edu/journals/hpu/summary/v023/23.4a.moore.html
Head and Neck Cancer Disparity in Underserved Communities: Probable Causes and the Ethics Involved

Charles E. Moore, MD, FACS
Rueben Warren, DDS, MPH, DrPH, MDiv
Sandy D. Maclin, Jr., MDiv, DMin

Abstract: Head and neck cancers are a cause of morbidity and mortality throughout the United States. For low-income, African American men they are one of the leading causes of excess cancer deaths: although all racial/ethnic groups suffer from these cancers, African American men disproportionately suffer and die from them. Low-income communities have increased risks for many adverse health conditions because of environmental factors and existing social determinants of health. These social determinants often lead to unhealthy life circumstances and ineffective coping behaviors. Early detection enhances effective treatment options, but such services are limited among African Americans, particularly African American men in underserved areas. Not addressing oral cancer because of these social conditions reflects unjust and unethical behavior by health care professionals. In Atlanta, one high-density, limited-resource area has the highest incidence of oral cavity cancers. Health Education, Assessment and Leadership (HEAL) was created to address the oral cancer incidence and prevalence, an example of a preventable health disparity between this underserved region and surrounding communities.

Key words: Disparity, health care, oral cancer, dental care, preventive health, underserved communities, African American men.

This article reviews the challenges in prevention, early detection, and treatment of head and neck cancer. The authors argue that the disproportionate burden of head and neck cancer borne by African Americans is unethical, because enough is known about prevention, early detection, and treatment to eliminate the disproportionate disease burden and health care disparities between African Americans and their...
non-Hispanic White counterparts. Plausible reasons for this problem include, but are not limited to two major challenges:

- Limited geographic and financial access to preventive and curative care, and
- Unwillingness by health professionals to address oral cancer disparities because of misperceptions and professional biases about African Americans, particularly African American men.

The authors conclude that knowing and not doing is unjust and unethical, particularly for the underserved.

In January 1984—10 months after becoming Secretary of Health and Human Services—Margaret Heckler sent Health, United States, 1983 to Congress. Like its predecessors, that report cited significant progress in public health: people were living longer; infant mortality had continued to decline. In fact, the overall health picture in the U.S. showed almost uniform improvement. But—and that but signaled a sad and significant fact—racial and ethnic disparities continued in the disproportionate burden of death and illness experienced by African American and other minority populations in the U.S. compared with the population as a whole.

Despite the unprecedented explosion in scientific knowledge and the phenomenal capacity of medicine to diagnose, treat, and cure disease, African Americans, Hispanics, Native Americans, and selected populations of people of Asian/Pacific Islander heritage were not benefiting fully or equitably from the fruits of science or from the systems responsible for translating and using health sciences technology. In April 1984, aware of the tragic fact of health disparities in the U.S., Heckler established the first Task Force on Black and Minority Health. Thus, this Task Force was conceived in response to a national paradox—phenomenal scientific achievement and steady improvement in overall health status but simultaneous persistence in significance health inequities for minorities.

Cancers, and head and neck cancers in particular, disproportionately and adversely affect African Americans. In introducing the 1985 Report of the Secretary’s Task Force on Black and Minority Health, Heckler wrote:

[T]here was a continuing disparity in the burden of death and illness experienced by Black and other minority Americans as compared with our nation as a whole. That disparity has existed ever since accurate Federal recordkeeping began more than a generation ago, and although our health charts do itemize steady gains in the health of minority Americans, the stubborn disparity remained . . . an affront to both our ideals and to the ongoing genius of American medicine. The Task Force Report was the first instance of the federal government acknowledging that health disparities could be chronicled by race and ethnicity, which was an important precursor to addressing this longstanding problem. The report also coined the term excess deaths to refer to deaths, usually preventable, that could not be fully explained by biomedical and/or public health research. These additional, presumably preventable, and unnecessary deaths were increased among African Americans compared with their non-Hispanic White counterparts. The sex- and age-adjusted
Head and neck cancer disparity in underserved communities

death rate among non-Hispanic Whites was used as a baseline for what should have occurred among African Americans, if the death rates of the two populations were the same. In 1985, six conditions resulted in 80% of the excess deaths among African Americans: cardiovascular diseases and stroke, cancer, cirrhosis, diabetes, homicide and unintentional injury, and infant mortality. In 1992, HIV/AIDS was recorded as the seventh cause of excess deaths among African Americans. By 2002, the reported number of excess deaths in African Americans had risen to 83,000, up from 60,000 in 1985. Clearly, a different strategy is needed to achieve health equity for those in greatest need. Moreover, considering past mistakes, bioethics and public health ethics violations must be identified and monitored to prevent them from reoccurring.

The impact of a head or neck cancer diagnosis can be devastating to patients and their families. Cancers in this area include tumors that arise in the nasal cavity, sinuses, lips, mouth, salivary glands, throat, cervical soft tissues, pharynx, and/or larynx. About 39,250 new cases will be diagnosed this year, and 11,090 affected patients will die from cancer-related issues. An encouraging fact is that cancer of the head or neck is treatable. The key is early detection.

Despite continued improvement in health care, health and health care disparities persist. African Americans are diagnosed with some form of cancer at a rate of 44 diagnoses per 100,000 individuals more than are non-Hispanic Whites. In addition, the death rate is 33% higher for all cancers among African Americans. Early detection helps to treat disease before extensive local destruction and local, regional, or distant metastasis occur. For cancer in general, early detection occurs in about 54% of non-Hispanic White Americans and 48% of African Americans. Reducing this difference could change survival rates significantly for African Americans. One likely reason may be limited geographical and financial access to care. Another plausible reason may be unrecognized bias by individual health care providers about African American men such as unacceptable responses to or noncompliance with recommended treatment options.

Because of their effect on the airway and gastrointestinal system, head and neck cancers usually cause symptoms early in the disease process. Disease stage at the time of diagnosis is a critical determinant of treatment options and prognosis for these cancers. Despite the presence of early symptoms, however, many Americans do not obtain treatment.

Methods

A convenience sample of 325 patients were evaluated at community screening events and community-based organizations (CBOs) that focus on homeless populations in medically underserved areas. During the screening visits a medical history, questionnaire and clinical examination of the head and neck were performed. No medical therapy was given at the screenings. Based on the findings from the physical examination and review of risk factors, 42 patients were referred to the appropriate health care facilities.

Screening clinics. All people at the given community event or CBO the day of screening were eligible for inclusion. The facilities were given advance notification of screenings. Flyers were posted to notify the homeless populations. The transient nature of the population contributed to varied participation at screening locations, as did the population’s willingness to participate. For example, some participants who had
only limited symptoms (e.g., tooth pain) declined participation when the scope of the examination was explained.

**Interview.** Demographic information was collected by questionnaire and interview, as well as other data regarding nutrition, transportation, and head/neck cancer risk factors such as alcohol and tobacco use. Interviews were conducted by a medical doctor at the time of examination, and the questionnaire was reviewed. Questions specifically targeting alcohol and tobacco were included in the questionnaire because of the risk of oral cancer associated with alcohol and tobacco use. People who could not complete the questionnaire because of low educational level or mental capacity were assisted by someone at the shelter or screening location. Tobacco use was categorized into cigarette, cigar, chewing tobacco, or snuff use. Alcohol use was categorized into beer, wine, and liquor consumption, and was further divided into current and regular use based on frequency. Information on the amount of alcohol consumed during each episode was not recorded, nor was the concurrent use of multiple forms of tobacco or use of alcohol with tobacco recorded, as the majority of the respondents did not say that usage as being concurrent.

**Clinical assessment.** The clinical assessment consisted of a full head and neck examination. This included examining the skin, cervical lymph nodes, bony structure of the external ear and auditory canal, oral cavity, anterior nasal structures, and oropharynx. Oropharyngeal examination was accomplished using a head light and reflective-mirror laryngoscopy. The head and neck regions also were palpated for masses, and the chest was auscultated with a stethoscope. All lesions were recorded. Patients with medical findings were placed into categories based on the degree of urgency for further therapy. Patients with acute infection or findings consistent with a neoplasm were given urgent follow-up information and directed to our clinic. Medication issues and other nonurgent problems were referred to the appropriate entity at the Grady Health System (Atlanta, Georgia).

**Data analysis.** Demographic characteristics, screening results, risk factors, and data regarding other medical issues were summarized using descriptive statistics. The relation between risk factors and the need for medical care and the risk of head/neck cancer was evaluated by use of c2 analysis and calculation of odds ratios (ORs) and relative risks (RRs), respectively, with 95% confidence intervals (CIs). Cigarette use was converted into a dichotomous variable (smoking ≥25 per day vs. nonsmoking) and daily alcohol consumption was split into three categorical variables (25 g, 50 g, or 100 g) for purposes of this analysis.

The study period extended from June 2005 to March 2008. A total of 325 patients participated in the screening process. Most participants were male and African American, with a mean age of 36 years. Thirty percent of them had at least some college education. Of the 325 participants, 255 responded to questions regarding tobacco use. Of these, 53% of participants smoked cigarettes, nearly 11% smoked cigars, and slightly more than 4% chewed tobacco or used snuff. For this population, there were fewer than expected nonsmokers. Among the 251 patients responding to questions about alcohol usage, just more than one-quarter of the patients were current drinkers, most often of beer. Reasons for not responding were personal, and all participants acknowledged understanding the question. In all, 71.2% knew that the use of tobacco can lead to lung
cancer, but 78.9% did not recognize that it also could lead to head and neck cancer. Among the 256 patients who reported at least one sign or symptom of head/neck cancer (41.4%), the most often reported was a change in voice (17.2%). Problems swallowing, skin changes, and persistent earache each were reported by 14% of patients. Despite the presence of these and other symptoms, however, nearly three-quarters of respondents had received no medical care (72.3%). All participants indicating a problem were referred for further evaluation if needed. Of these, 28 (11%) were referred specifically for further head and neck cancer evaluation. Of these, 22 (80%) underwent further evaluation and biopsy at the designated health facility. Of those that had a biopsy, two (9%) were found to have a malignancy, which was later treated. The use of tobacco increased the need for medical follow-up. Cigarette smoking was associated with an OR of 2.309 (95% CI, 1.332–4.371) for this outcome. Alcohol use was associated with an OR of 1.450 (95% CI, 0.985–3.212) with the need for medical follow-up. (In addition, daily consumption of 25 g, 50 g, or 100 g pure alcohol was associated with a pooled RR of 1.75, 2.85, and 6.01, respectively, of oropharyngeal cancer.) Nondrinkers who smoked 25 or more cigarettes per day had a seven-fold increased risk of oropharyngeal cancer compared with nonsmokers.

Discussion

The lead author (CM) is the Chief of Service at Grady Health System, in the Department of Otolaryngology at Emory University. After numerous encounters with patients who sought medical care only after their cancer had progressed to the point where they had limited treatment options (Figures 1a–c), he decided that more was needed to increase awareness of head and neck cancers among the local population. To continue to wait until these cancers were in their late stages was unjust and unethical, when the impact of early detection is well documented.

Grady is the major public hospital in Atlanta. The three ZIP codes that represented the highest percentages of head and neck cancers in the state all were located within Grady’s catchment area, and all three were in medically underserved areas. These ZIP codes therefore were targeted for educational intervention on and screenings for head and neck cancers, focusing primarily on homeless shelters and faith-based institutions within these areas (Figure 2).

As the educational process continued, other colleagues and medical residents began participating in this activity (Figures 3a–c). If health problems or suspicious lesions were found, individuals were referred to appropriate health care professionals for long-term treatment. Contrary to the perception that people from underserved areas do not keep appointments, particularly follow-up appointments, about 80% of people who were found to have lesions of concern kept their follow-up appointments in the Grady otolaryngology clinic for definitive treatment. However, only 9% of the people screened had early cancerous lesions (Figures 4a–d).14 What became clear as this effort evolved was the need for treatment to complement the educational and screening activities.

In 2004, Health Education, Assessment, and Leadership (HEAL) organization15 was founded to provide health education and medical services to underserved areas. This program began as a mobile educational resource operating out of an automobile, which
Figure 1a. Patient evaluated at Grady Health System, which provides care for indigent individuals in the metropolitan Atlanta area.

Figure 1b. Patient evaluated at Grady Health System.
later was replaced by a mobile unit (Figure 5a). The HEALing Community Center (Figure 5b) was then conceptualized as a free-standing medical facility that would provide health education and primary and specialty care services in the ZIP codes that need them most. Through collaborations with multiple medical, faith-based, community, and academic organizations, the Center currently provides direct services in a medically underserved inner-city area in Atlanta. The facility addresses the increasing health disparities disfavoring minorities and uninsured individuals in poverty.

Many health professionals serve as medical volunteers, and these volunteers are needed as part of the solution to making medical care more accessible. No action is too small. Yet volunteerism is no replacement for a “health care home” supported by a full-time health care team. Federally funded community health services are the ideal mechanism for providing high-quality primary care, particularly for underserved populations. Whether the focus is on the local, national, or global level, we can make tangible improvements to direct patient care, health education, public health, or the

Figure 1c. Patient evaluated at Grady Health System, which provides care for indigent individuals in the metropolitan Atlanta area.
Figure 2. Head and neck cancer screening check-in at a homeless shelter in Atlanta.

Figure 3a. Patient and Dr. Ajani Nugent (facing) in a mobile unit at a community head and neck cancer screening event.
Figure 3b. Medical student, Dr. Oswaldo Henriquez (middle), and patient at a mobile head and neck cancer screening event.

Figure 3c. Dr. Elina Kari (left) and a patient during a head and neck cancer evaluation at the HEALing Community Center.
Figures 4a–d. Lesions identified during mobile head and neck cancer screenings.

Figure 4b.
Figure 4c.

Figure 4d.
health care infrastructure. In the process, hope, possibility, and expectation can be restored among those who are too often underserved.

As in most cities, the availability, accessibility, and acceptability of health care do not meet the demands. Marginalized populations in Atlanta have grown unrelentingly. In the first Atlanta homeless census in 2003, the homeless population was 6,956. Within one year, this population had grown to about 12,000–20,000.³,⁵,⁷,¹³,²² To combat this issue, several community outreach centers and homeless shelters exist. These safety-net organizations cannot address all of the issues confronted by this population, however, including providing health care that is appropriate, accessible, and acceptable.

Every year, new people face unexpected hardship. On any given day in the United States, at least 800,000 and as many as three million people are homeless.¹⁶,¹⁷ A myriad of factors can contribute to the onset of homelessness. Issues related to low wages or unemployment, racial discrimination, and a lack of affordable housing, either alone or combined with issues of drug abuse, domestic violence, and physical and/or mental illness can put unsuspecting people at risk. Poverty inevitably produces serious health problems, but screening with physical examination can help reduce the mortality associated with cancerous lesions.¹⁸ Unfortunately, most underserved populations do not have the means to have sustainable health insurance or the financial capability to cover the costs of health care.¹⁹

In 2002, the overall proportion of the U.S. population living in poverty was 12.1%,
up from 11.7% in 2001 and 11.3% in 2000, marking the first increase in the poverty rate since 1993. More than half of the African American and Hispanic children under age 18, and more than half of the African American and Hispanic adults over age 65, were either poor or near-poor. In light of the economic decline over the past few years, the population lacking affordable, accessible health care has no doubt increased further.

Major changes continue to occur in the delivery of health care in the U.S., partly driven by changes in payment policies intended to rein in rising costs and by advances in technology that have allowed more complex treatments to be performed on an outpatient basis. These services have contributed to the decline in hospitalizations, and many procedures are being geared towards outpatient care. For example, in 2002, 63% of all surgical procedures in community hospitals were performed on outpatients, up from 51% in 1990 and only 16% in 1980. However, the health of the nation also has continued to improve overall because of resources devoted to health education, public health programs, health research, and health care. The ethical problem is that these improvements have not been equally beneficial to all.

Many reports indicate an increase in health services focused on prevention and early detection. A major concern still exists about the accessibility of health care as a determinant of people's ability to use and pay for care. Reports often fail to address the disparities in risk factors, access, and utilization according to race, ethnicity, and socioeconomic status. As the nature of health care has changed, the supply of health care has increased.

Figure 5b. HEALing Community Center in Atlanta.
HEAL = Health Education, Assessment and Leadership
providers and the sites where specific services are provided also have been evolving.\(^20\) Such evolution has demonstrated cost-effectiveness only in terms of insurance payments, however, with profitability outcomes outweighing the ethical position of human capital over economic capital gain.

It is critical to direct head and neck cancer screening programs towards high-risk populations, specifically those that include men, people with a history of tobacco and/or alcohol dependence, and people of low socioeconomic status.\(^21,22,23\) Underserved populations are concentrated in urban areas but are also often found in rural areas. In both cases, access to health care services can be difficult at best, not only because of the cost, but also because of a lack of transportation. Moreover, low-cost preventive health care is often nonexistent. To our knowledge, HEAL Head and Neck Cancer Outreach is the only active community outreach group that targeting the underserved and homeless populations and focusing specifically on head and neck illnesses.

Although screening exams can be effective for outcomes research, as stated previously, underserved populations face several barriers to health care access.\(^24–26\) In addition, several studies of screening for head and neck cancers in high-risk populations have shown poor compliance with follow-up, particularly compared with breast cancer screening programs.\(^25,26\) Screening with no follow-up is unjust, unethical and an ineffective use of resources. A concerted effort is imperative if improvement is expected. Notably, 80% of participants in our study who were asked to follow up at a designated facility for further head and neck evaluation did so.\(^14\) Statements were made by those coming for further evaluation that “I have never had anyone show any interest in me or my health to this extent before . . . so I was determined to get checked out,” and “You made the effort to come to us to help me so the least thing I could do was follow up.” This feedback may indicate that health care professionals should rethink their approach to patients, ensuring that their interest in promoting health and wellness is a priority. Health screenings in underserved populations might improve compliance by establishing communities that provide participants with shelter, food, job training, and health care. Such settings offer a greater chance for long-term medical relationships to develop, which we hope will improve effectiveness.

In conclusion, underserved populations most often live in high-risk areas. Numerous circumstances contribute to the perceived difficulty of providing health care to this population. Extensions beyond conventional medical facilities are a means to reach this underserved population. Community outreach programs are an excellent starting point to improving health care access. By these methods, comprehensive, quality care can be delivered in a cost-effective manner. Risk factors for head and neck cancer, such as tobacco and alcohol use, are likely to be increased in underserved populations compared with other cohorts, due to uncontrolled social determinants.\(^5,6,8,9,13,22\) The data collected are encouraging and demand more efficient and effective strategies for serving underserved communities. Of equal importance, this study shows the need to increase education and awareness of all of the ramifications of the use of tobacco products. The ethical problem can be assessed using the Bioethical Decision-Making process described by Sodeke:\(^27\) Facts of the Case (FOTC); Preference of the Stake Holders (POSH); What Happens if we do Noting (WHDN); What would be Best to Do (WBTD)?

**FOTC.** Head and neck cancers are a leading cause of death in the U.S. These cancers
disproportionately affect African Americans, particularly African American men. These cancers are largely preventable by early detection and treatment.

**POSH.** The stakeholders include, but are not limited to the following: The resident community (all family members), publicly elected and appointed officials including the mayor, public health and safety officials, local commercial businesses, the research community, and the general public.

**WHDN.** The ethical problem heightens and the public health problem worsens. The quality of life in community suffers and an ethos of hopelessness and helplessness may heighten.

**WBTD.** Using the step-wise process of assessment, advocacy, coordination and evaluation and including the principles grounded in community-based participatory research an effective strategy can be implemented.

The challenges in eliminating head and neck cancer disparities and reducing the prevalence of these and other preventable diseases, disabilities, dysfunction and conditions can be better addressed if spheres ethics are considered by health professionals in order to meet the needs of their service populations.28

**Disclaimers**

The authors have no conflicts of interest or previous publications on this research project to declare.

**Notes**