A. 2004 American Cancer Society Report: Addressing Disparities

Harmon J. Eyre, MD

Chief Medical Officer, Research and Cancer Control Science American Cancer Society

Cancer is the second-leading cause of death in the United States and the leading cause of death in Americans younger than 80 years. More years of life are lost from premature death due to cancer than from heart disease. This disease represents an area in which primary care practitioners can have an enormous positive effect.

In the early-to-mid 1990s, the American Cancer Society (ACS) conducted a futuring study that examined predictions ranging to 20 years in the future and, on the basis of this study, presented the nation with three goals to attain by the year 2015. These goals included a 50% reduction in age-adjusted cancer mortality rates, a 25% reduction in age-adjusted cancer incidence rates, and a measurable improvement in the quality of life from time of diagnosis for all cancer survivors. These goals drive ACS programs and initiatives.

The age-adjusted cancer incidence rates peaked in 1992 and have been declining steadily (Figure 1). The initial drop was precipitated by a decrease in prostate cancer that came about with the widespread use of prostate-specific antigen tests. Further declines have been attributable to real and measurable decreases in lung and colorectal cancer incidence.

Cancer mortality rates have also decreased from the 1991 level of 215.1 deaths per 100,000 population per year, although this decrease has not been sufficient to meet the year 2015 goal of 50% reduction (Figure 2). The age-adjusted incidence of lung cancer has peaked in women. The last years for which data are available, 1999, 2000, and 2001, the incidence has decreased 2.4% per year. Lung cancer mortality will similarly decline, and this decline is expected to accelerate.

African Americans have increased rates of most types of cancer; these disparities are more prominent in men than in women. African Americans also suffer increased mortality from all cancers, compared to their White counterparts, although Asian-American, American-Indian, and Hispanic populations all experience lower mortality than White populations (Figure 3). This difference is attributable primarily to differences in the most common cancers and is most profound in men. The difference is less profound, but still significant, among women.

Disparity rates for all the common cancers, by cancer, are available in the 2004 Cancer Facts and Figures. To obtain a copy, call the American Cancer Society call center at 1-800-ACS-2345. It may also be downloaded from www.cancer.org by typing in "Cancer Facts and Figures" in the search field.

Cancer disparities are influenced by social, economic, and cultural factors that far overpower the contribution of racial or genetic factors. Unfortunately, these factors affect the entire cancer "spectrum," from prevention, detection, and diagnosis to treatment, post-treatment quality of life, and survival. The plan for reducing these disparities begins with primary care, in a system that promotes health, wellness, and early detection, when cancer can be cured. Advocacy represents an area rich in possibilities for improvement, in areas of affordable health insurance and public policies that reduce tobacco promotion to low socioeconomic status populations. Culturally appropriate care should be fostered, and education on primary and secondary disease prevention should be targeted to minority populations. The Centers for Disease Control and Prevention breast and cervical cancer

Ethn Dis. 2005;15[suppl 2]:S2-62-S2-67



Fig 1. Age-adjusted incidence of invasive cancer (all sites) by year of diagnosis. The goal for 2015 is a 25% reduction from 1992 incidence of 509.9 per 100,000 population per year

early detection program is a model program for reducing health disparities and improving outcomes.

In summary, major disparities exist across the entire spectrum of cancer, affecting prevention, early detection, treatment, survival, and palliative care. Poverty and lack of access to high-quality health care are problems that are increasing rather than decreasing. Despite overall progress against cancer, these disparities present profound moral, social, and scientific challenges to the nation.

B. PRIMARY CARE FOR THE 21ST CENTURY

Marilyn Gaston, MD

Former Assistant Surgeon General and Director of the Bureau of Primary Health Care in the Health Resources and Services Administration, US Department of Health and Human Services

Seven main areas are targets for redesigning the healthcare system: access; quality; disease prevention and health promotion; self-care; technology; health outcomes; and training. These areas are receiving increasing attention from clinicians, researchers, and policymakers, driven by the series of Institute of Medicine policy reports. Barriers exist in the form of finance, geography and capacity, language and culture, attitudes, education and health literacy, and society.

ACCESS TO CARE

Access should target three main areas: access to quality care, access to affordable medications, and access to medical information. Lack of health insurance is the fifth leading cause of death in the United States, accounting for 18,000 preventable deaths each year. Evidence shows that universal, singlepayer health care is financially possible; lack of political will is the primary obstacle to achieving this goal. Individuals should urge their elected officials to more aggressively pursue this outcome.

The first step to universal access is changing the healthcare system. While this may seem like a daunting task, it is being done in communities around the country. The current healthcare model is top-heavy, with treatment on the tertiary care side receiving a disproportionate amount of resources and attention. A more ideal model would be based on a solid foundation of prevention and early diagnosis on the primary care side, followed by fewer resources focused on secondary care, with tertiary care occupying only the narrow peak of the healthcare pyramid.

Another way of viewing the existing healthcare model is with the emergency room at the center. In this model, patients' point-of-entry into the system is through emergency services. This model is unsustainable because it is fragment-







Fig 3. Death rate from all cancers among US men by race, 1975-2000

ed, uncoordinated, costly, dysfunctional, and difficult to navigate. For health care in the 21st century, primary care must be at the center of the model (Figure 4).

In areas where this model is being implemented, the process is being carried out only with a great deal of community involvement and input. All healthcare "stakeholders" have input into the redesign of their system. This point is critical to accomplishing these goals.

QUALITY

Care should be safe, effective, patient-centered, timely, efficient, and equitable. Delivery of quality care depends on effective and evidence-based practices. Cultural competence must permeate care, and it must be monitored. Health literacy of clients needs to be measured and, if necessary, addressed. Additionally, in order to maximize the quality of care, the system must be monitored for inherent biases, prejudices, and all "-isms" (eg, racism, sexism, ageism).

DISEASE PREVENTION AND HEALTH PROMOTION

Disease prevention has improved in our healthcare system; however, less than 3% of healthcare resources are dedicated to prevention. Increasing this focus is critical to improving health. Additionally, practices should focus on, not only disease prevention, but wellness and increasing the quality of life, with an overall, holistic approach to health. This model should integrate mental/ emotional health and spiritual health, as well as physical health. Providers should address, as a function of healthcare delivery, prayer and other sources of spiritual support. Everyone must have a daily living plan for disease prevention and health promotion.

Self-care

A revolution is in progress in patient self-care. Healthcare provision must be patient-centered; each person must be a true partner in his or her care. Patients in the United States have a deep "hunger" for healthcare information, but many confusing and often contradictory sources for this information exist, from the Internet to popular television programming (eg, "Oprah" and "Dr. Phil"). Another area in which more work needs to be done is in making patients feel safe and confident with their



Fig 4. Redesign to a primary-care centered system. In this model, the point-of-entry into the healthcare system is through primary care and prevention

Table 1. Seven core principles in support of a renaissance of primary care

- 1. Health care must be organized to serve the needs of patients.
- The goal of primary care systems should be the delivery of the highest-quality care as documented by measurable outcomes.
- 3. Information and information systems are the backbone of the primary care process.
- 4. Current healthcare systems must be reconstructed.
- 5. The healthcare financing system must support excellent primary care practice.
- 6. Primary care education must be revitalized, with an emphasis on new delivery models and training in sites that deliver excellent primary care.
- 7. The value of each care practice must be continually improved, documented, and communicated.

Adapted from Ann Intern Med. 2003;138(3):268-272.

care; clinicians must work to earn patient trust. Accomplishing this goal will empower patients to share in their healthcare decision-making; however, the healthcare team must also work to feel secure with patient empowerment. Patients have the right to ask questions and help develop treatment plans, and they must know about and act on this right. Patients are the source of control of their health care.

TECHNOLOGY

In a world where technology allows persons to access money and financial information from anywhere on the planet, no excuse can be given that medical records and information are not similarly available. Medical records should be electronic, and systems of care must be interconnected. In areas where healthcare systems are being redesigned as discussed above, technological transformation of records and use of common forms have been crucial to bringing about desired changes. In these models, patients and physicians can readily access this information.

HEALTH OUTCOMES

In order to make all the needed changes to the healthcare system, practices must be outcome-driven. The bottom line is not costs or testing, but rather patient outcome, and this outcomedriven healthcare-delivery system must be monitored, led by both providers and consumers. Consumers must have a great deal of input in this area. Health outcomes must be measurable, and the system must change from being treatment-focused to being prevention-focused, that is, to paying for health rather than health care.

TRAINING

Training encompasses all other elements of redesigning healthcare: quality, cultural competence, health literacy, health promotion, and others. This training should not be targeted exclusively to future providers; all current providers must also receive training in these areas. Better health for more people for less cost is a definite and achievable reality in the United States. As Goethe said, "Knowing is not enough; we must apply. Willing is not enough; we must do."

C. PROVIDING Compassionate Primary Care

Yvette Williams, MD, MPH

Assistant Professor, Emory University School of Medicine Atlanta VA Medical Center

Compassionate care is a difficult term to define. If a patient leaves a clinician's office, believing that the clinician genuinely cared about him and his problems, then compassionate care has probably been delivered. Compassion is not the only important, and may not even be the most important, aspect of general medical care. However since primary care clinicians seek to achieve long term behavioral change, being compassionate may be the most important attribute of a primary care clinician. Patient-centered care is a less fuzzy description of compassionate care.

The Institute of Medicine, in their 2001 Crossing the Quality Chasm¹ report defined this as "care that is responsive to the needs, values, and expressed preferences of the individual patient." This type of care has two dimensions: 1) clinicians must engage each patient in a process of making and prioritizing healthcare decisions; and 2) clinicians should demonstrate emotional sensitivity toward each patient's circumstances.

Delivering patient-centered care does not mean that the physician decides what a patient's issues are and single-handedly builds a plan to address them. Instead, physicians should ask patients what their issues are, explore their motivations, and help them come to a solution on their own. This process paves the way for patients to make significant, lasting changes. Patients leave the office saying to themselves not, "I'm going to do what the doctor said," but rather, "The doctor helped me understand what I need to do for myself." Showstack et al in the Annals of Internal Medicine² suggested a reorganization around seven core principles. Patientcenteredness is at the core of these principles (Table 1).

Health care must be organized to serve the needs of patients. Currently, much of the organization of medical care is structured to meet the needs of the reimbursement system or preferences of clinicians. Care must be patientcentered. Other industries learned this principle long ago; the banking industry, for example, has taken advantage of technologic advances to provide its customers with improved services on a

PLENARY SESSION 1A

schedule that meets customers' needs. Similarly, as care is revolutionized in the United States, patients must be able to access care when they need it.

The goal of the healthcare system should be delivery of the highest quality care, as documented by measurable outcomes. Population-based medicine is useful and important, but clinicians still need to focus on individual outcomes.

Information and information systems are the backbone of the primary care process. Primary care physicians have lamented for years that information systems have been available for other industries, but not for health care. The Veterans Administration (VA) sector of health care is ahead of other sectors in this regard. A physician can easily access a new patient's medical records from across the country through the VA medical information system. This kind of model needs to be adopted by providers across the country. Current healthcare systems must be reconstructed. The system is broken and must be fixed.

The healthcare financing system must support excellent primary care practice. Reform of the finance system will be crucial to attaining other goals in the healthcare revolution. Primary care education must be revitalized, with an emphasis on new delivery models and training in sites that deliver excellent primary care. Medical schools must teach students and residents in the primary care setting, and they must learn that care needs to be patient-focused.

The value of primary care practice must be continually improved, documented, and communicated. Change should be expected. Clinicians should focus on assessment, planning, implementation, and monitoring. Only through these continuous cycles of change can the healthcare system be improved.

References

1. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Cen*tury.* Washington, DC: National Academy Press; 2001.

 Showstack J, Lurie N, Larson EB, Rothman AA, Hassmiller S. Primary care: the next renaissance. Ann Intern Med. 2003;138(3):268– 272.

D. Assessing Pennsylvania's Changing Nurse Workforce

Calvin B. Johnson, MD, MPH

Quality of care and compassionate care are embodied in nursing and the nursing workforce. Early in their training, physicians learn the value and utility of nurses. In Pennsylvania, as across the nation, legislators, policymakers, and stakeholders have been talking about the nursing shortage, although much of this talk of problems and solutions has occurred in the absence of real data. The Pennsylvania Department of Health responded to this discussion with the need to obtain objective information to inform the discussion.

METHODS

The Pennsylvania Department of State renews nurses' licenses in four cohorts over two years. The Pennsylvania Department of Health attached to the licensing renewal application a survey of 22 questions designed to collect data on demographics, education, professional experience, employment, and job satisfaction. Data on educational programs were refined by using Department of Health data on annual school programs and accreditation. The renewals and surveys were sent in April and October 2002 and April and October 2003. Approximately 83% of RNs and 96% of LPNs completed the survey, for a total of more than 152,000 RN and 46,000 LPN responses in this sample. Since every nurse who holds a license is not actively working in health care, this sample represents approximately 55% of the

total nursing workforce in Pennsylvania. Data were analyzed by the Department of Health's Bureau of Health Statistics and Research.

RESULTS

Key findings included that approximately 95% of respondents were female, and their average age was 45.4 years. The working-age population in Pennsylvania is 8.9% African-American, but only 2.9% of the nursing workforce is African-American. Approximately 2.5% of the population in Pennsylvania is Hispanic, but only about 0.72% of the nursing workforce is Hispanic. Of the respondents, 85% were educated in Pennsylvania, and a majority were satisfied with their jobs and careers.

Approximately 33% of the nurses in Pennsylvania hold a Bachelor's degree, 33% received their diplomas through hospital programs, 22% have an associate degree, and 10% have a Master's degree. Fewer than 1% of Pennsylvania nurses have a doctorate-level degree.

Of nurses younger than 35 years, a significant number (28% of RNs and 20% of LPNs) indicated that they intended to leave the nursing workforce within 10 years. This finding indicates that, even if no nursing shortage exists in Pennsylvania, the potential for a shortage to occur in the near future is real.

When asked to identify factors that increased their job satisfaction, nurses identified co-worker relationships, physician relationships, hours and scheduling, clinical excellence, their supervisors, and technology. Factors that decreased job satisfaction were administration's value of RNs, lack of participation in decision-making, salary and benefits, lack of career development opportunities, staffing levels, and paperwork. Many of these factors can be controlled or addressed on an administrative level.

Capacity is an issue in nursing education. Insufficient faculty are available to educate the needed workforce. In 2003, 126 nursing education programs existed. Between 1999 and 2003, RN program enrollment increased by 59%. In all programs, student/faculty ratios are increasing, and fewer venues are available for clinical training.

CONCLUSIONS

Based on these results, the Pennsylvania Department of Health developed a white paper that was provided to clinicians and policymakers and is available on the web at http://www.health. state.pa.us. This type of evidence-based, data-driven information is essential to informing public health and policy decisions on all levels.

The following recommendations from the White Paper The Nurse Workforce In Pennsylvania are intended to share the insight and wisdom of the task forces that studied the issues, and offer conceptual considerations and approaches to policy-makers, legislators, educators, industry leaders, and others to consider when focusing in on systems-based solutions.

- 1. State government, educators, and employers should collaborate to develop strategies to increase the numbers of members of cultural, racial, and linguistic minorities who enter and graduate from nursing programs.
- Schools of Nursing and health industry leaders should create an ongoing dialogue between employers and educators aimed at assuring an

informed and consistent approach to the education of nurses.

- 3. In order to meet the rapidly changing needs of the healthcare industry, nurse education and training must remain flexible in adapting to an environment in constant change.
- 4. Faculty are the major building blocks in developing nurses who will meet the future healthcare needs of Pennsylvania. A policy consortium such as the Workforce Investment Board's Center for Health Careers should take steps to develop and implement strategies to retain current nurse faculty, support the development of nursing faculty, and explore new sources of nurse faculty.
- 5. Because the components of nurse education are diverse but interrelated, proposed strategies to increase the supply of nurses in the Commonwealth should reflect a systems approach that encompasses faculty development, student recruitment, school capacity, clinical capacity, and employer needs.
- 6. Attrition from nursing programs represents a loss of important resources, particularly when waiting lists for admissions are high. Nursing students who drop out or change programs represent a lost resource. Nursing schools should collaborate to develop programs to reduce student attrition.
- 7. Identify and refine strategies to recognize the impact that generational factors have in the workplace and address the factors as a way of reducing employee turnover and intergenerational tension.

- 8. Nursing has evolved into a multifaceted and fast paced health profession. The rapidity of change in the healthcare industry demands a commitment to lifelong learning. Ability to meet these changes directly may be tied to turnover, job and career satisfaction, and patient safety.
- 9. Employers, state, and federal government agencies should remain flexible and open to policies and regulations that promote the retention of nurses in the work place.
- 10. Additional research on refining Pennsylvania specific supply and demand estimates for RNs and LPNs in the workplace that take into account demographic changes is needed. The research should focus on the development of specific workforce targets and form the basis for policy development and the evaluation of the effectiveness of nurse workforce strategies.
- 11. The Nurse Retention Assessment Index of counties at risk for experiencing nurse shortages can provide interim information to policymakers interested in targeting recruitment/retention priorities. Use of these targets would allow for the most effective use of public and private resources aimed at stemming a developing shortage of nurses.

In April 2004, Governor Edward G. Rendell announced the establishment of the Pennsylvania Center for Health Careers, a significant step in the development of a coordinated systems approach and opening the possibility for legislative initiatives.