

THE MARYLAND COMPREHENSIVE CANCER CONTROL PLAN

OUR CALL TO ACTION

2004-2008

**THIS CANCER PLAN IS DEDICATED TO ALL
THE COURAGEOUS MARYLANDERS AND
THEIR FAMILIES WHO FIGHT OR HAVE
FOUGHT A BATTLE AGAINST CANCER.**

**THE 2004-2008 MARYLAND COMPREHENSIVE
CANCER CONTROL PLAN SERVES AS A
MONUMENT TO YOUR VALIANT EFFORTS.**

**"TO BE EFFICIENT AND EFFECTIVE,
WE MUST WORK WITH OUR
PARTNERS TO CHANGE THE CATEGORICAL
CANCER MINDSET INTO ONE
COMPREHENSIVE STRATEGY."**

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Over the course of a two-and-a-half year planning process, citizens from around the state of Maryland donated their time, expertise, and experience to the development of the 2004–2008 Maryland Comprehensive Cancer Control Plan (MCCCCP). Many individuals and organizations contributed to the development of this plan.

Thanks must first go to the individuals who made up the Core Planning Team and the committees that were charged with developing the various chapters of this cancer plan. The combined efforts of the researchers, lay citizens, public health staff, and health care providers that served on the Core Planning Team and on committees resulted in chapters that truly capture current issues in cancer control and offer strategies that will make an impact on the cancer burden in this state. A list of committee members is provided at the beginning of each chapter.

Researchers and faculty at the University of Maryland, Baltimore's Greenebaum Cancer Center and School of Medicine and at Johns Hopkins University's Bloomberg School of Public Health and The Sidney Kimmel Comprehensive Cancer Center provided invaluable assistance. In addition, researchers from the Specialized Programs of Research Excellence (SPORE) programs at Johns Hopkins University interpreted and presented data to the various committees involved with this plan. The American Cancer Society contributed to the planning effort by providing representation on the Core Planning Team and every working committee.

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Finally, we thank the citizens of Maryland for embracing the concept of comprehensive cancer control and sharing their views by attending town hall meetings, providing feedback via the cancer plan website, and participating on committees.

EXECUTIVE SUMMARY

The Maryland Comprehensive Cancer Control Plan 2004–2008: Our Call to Action is a resource and guide for health professionals who are involved in planning, directing, implementing, evaluating, or performing research in cancer control in Maryland. This plan represents the coordinated effort of over 200 individuals across the state that came together through 14 committees and a Core Planning Team to develop a document that reflects the needs of Marylanders. This plan was not developed by, or for, any one organization. It was developed by a broad partnership of public and private stakeholders whose common mission is to reduce the burden of cancer in Maryland. This plan was developed by Marylanders for Marylanders.

The State of Maryland Department of Health & Mental Hygiene, on behalf of many partnering organizations, received a cooperative agreement from the Centers for Disease Control and Prevention in 2001 to develop a comprehensive cancer control plan for the state. Although there have been two previous Maryland Cancer Control Plans, this plan is more comprehensive in nature and has involved the participation of broader and more diverse organizations in its development than did the previous two plans.

Comprehensive cancer control is defined by the Centers for Disease Control and Prevention as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.” Comprehensive cancer control is an emerging model that integrates a range of cancer control activities to maximize the use of limited resources to achieve desired cancer prevention and control outcomes. The structure of this plan follows the CDC’s definition of comprehensive cancer control. This plan includes chapters that cover cancer control from primary prevention through survivorship and palliative care. Although there are over 100 different cancer sites, it was not feasible to cover every cancer site in this plan. Rather, this plan covers those cancer sites, interventions, or issues that we know from research will have an impact on cancer incidence, morbidity, mortality, and quality of life.

The plan starts with a chapter describing an overview of the burden of cancer in Maryland and a cancer control model for the state. The Plan is then divided into sections. The first section deals with primary prevention of cancer. Chapters in this section focus on tobacco-use prevention and cessation and lung cancer, diet and physical activity, ultraviolet radiation and skin cancer, and environmental issues. The second section addresses secondary prevention or the early detection and treatment of cancer. Chapters included in this section are cancer site-specific. There are individual chapters on breast, cervical, colorectal, prostate, and oral cancer. The next section deals with tertiary prevention. Chapters included in this section cover pain management and end-of-life care. The remaining chapters of the plan highlight crosscutting issues that are of importance to cancer control including cancer disparities, cancer surveillance, and patient issues and cancer survivorship. The Preface describes the background, the past Maryland Cancer Plans, and the processes used to develop the Comprehensive Cancer Control Plan. The Appendix contains information on data sources and methods.

Each chapter was written and/or edited by 10 to 20 Maryland experts in that area. A committee was formed for each chapter, and in general consisted of epidemiologists, health care providers, researchers, cancer survivors, and other representatives from local and state health departments, governmental agencies, community-based organizations, academic health centers, hospitals and other health care facilities, and cancer support groups. Committee members, as well as guest speakers and chapter contributors, are listed at the beginning of each chapter.

Each committee reviewed epidemiologic data, scientific research, and existing programs and resources, espe-

cially those available in Maryland. They identified gaps and barriers to cancer control in Maryland for the issues addressed in their respective chapter, and from these developed goals, objectives, and strategies. In general, the outline of each chapter is as follows: a review of data in Maryland relevant to the chapter's topic, a discussion of disparities, existing programs and resources, gaps and barriers, and then a section listing goals, objectives, and strategies. In addition, each chapter has a measurable target for change.

The goals, objectives, and strategies that are provided at the end of each chapter serve as a guide to all organizations in the state and show areas where additional attention is needed. The objectives are far-reaching and complex. No one organization can carry out all of these activities. Rather, these goals, objectives, and strategies are listed as our call to action to encourage any organization involved in any aspect of cancer control to address one or more of these goals and objectives, and apply the appropriate strategies as resources and opportunities arise.

Following is a list of the goals and objectives for each chapter in the plan. The objectives relate to public education, professional education, service delivery (such as screening, diagnosis and treatment), health insurance issues, research, access and utilization, data collection, analysis, and dissemination and policy issues. Specific recommended strategies for each objective are found in the goals, objectives, and strategies sections of each chapter.



Executive Summary Goals and Objectives

Chapter 2: Cancer Surveillance

Goal:

Fully implement cancer surveillance—the development, collection, analysis, and dissemination of cancer information—in Maryland.

Objective 1:

Develop, maintain, and enhance data systems to ensure accurate, timely, and complete information needed for the prevention and control of cancer.

Objective 2:

Expand access to, and analysis of, the databases used for cancer surveillance in Maryland in order to better meet the information needs of program planners, policy makers, researchers, and the public.

Objective 3:

Broadly disseminate cancer surveillance findings to promote cancer awareness, policy development, and implementation of cancer control programs.

Chapter 3: Cancer Disparities

Goal:

Reduce cancer health disparities in Maryland.

Objective 1:

Increase public and community awareness about cancer health disparities and cancer prevention, screening, and treatment in Maryland.

Objective 2:

Develop and implement health care programs designed to reduce cancer disparities among targeted populations in Maryland.

Objective 3:

Increase cancer disparities documentation and intervention on a systematic basis in Maryland.

Objective 4:

Increase provider education and reimbursement aimed at reducing cancer disparities.

Objective 5:

Improve access to, and utilization of, cancer screening and treatment options for underserved populations.

Objective 6:

Improve the quality of cancer care received by racial/ethnic minorities.



Chapter 4: Patient Issues and Cancer Survivorship

Goal:

Enhance the quality of life for all cancer survivors in Maryland.

Objective 1:

Enhance access to information and resources for Maryland cancer survivors, their friends, and families.

Objective 2:

Reduce the financial burden on cancer survivors and their families.

Objective 3:

Ensure that all cancer survivors have access to psychosocial support services throughout all phases of their cancer experience.

Objective 4:

Address the needs of long-term cancer survivors in Maryland.

Chapter 5: Tobacco-Use Prevention and Cessation and Lung Cancer

Goals:

Substantially reduce tobacco use by Maryland adults and youth.

Substantially reduce youth and adult exposure to secondhand smoke.

Objective 1:

Fund Maryland's comprehensive Tobacco-Use Prevention and Cessation Program at least at the minimum level recommended by the Centers for Disease Control and Prevention.

Objective 2:

Establish public policy that supports state and local bans on smoking in all public places and workplaces.

Objective 3:

Increase the excise tax on cigarettes to \$1.50.

Objective 4:

Enact civil prohibition on the sale of tobacco to youth under 18 years of age.

Objective 5:

Ensure access to tobacco-use cessation services.

Objective 6:

Enhance existing program activities.

Objective 7:

Continually evaluate and improve state and local programs.



Chapter 6: Diet and Physical Activity

Goal:

Reduce the burden of cancer in Maryland through the promotion of healthy diet, healthy weight, and physical activity as a means of cancer prevention.

Objective 1:

Increase awareness of and demonstrate healthy eating and physical activity patterns among Maryland families and communities.

Objective 2:

Increase the prevalence of healthy diet, healthy weight, and physical activity among Maryland youth.

Objective 3:

Increase access to a healthy diet and physical activity at Maryland workplaces.

Objective 4:

Increase the number of health care providers offering preventive nutrition and physical activity services.

Objective 5:

Engage the public with appropriate health messages related to nutrition, obesity, physical activity, and cancer via the media.

Objective 6:

Increase scientific knowledge regarding the relationship among nutrition, physical activity, and cancer.

Chapter 7: Ultraviolet Radiation and Skin Cancer

Goals:

Prevent increases in mortality from melanoma cancer.

Increase utilization of sun-safe behaviors.

Objective 1:

Increase public awareness about sun safety and skin cancer.

Objective 2:

Increase physician awareness about sun safety and skin cancer.

Objective 3:

Increase the number of melanoma cancers diagnosed at an early stage.

Objective 4:

Develop improved data to document the prevalence of skin cancer examinations and appropriate diagnosis and follow-up of melanoma and other skin cancers in Maryland.

Objective 5:

Implement policy changes to increase the use of sun-safe behaviors, particularly among youth in Maryland.



Chapter 8: Environmental Issues and Cancer

Goal:

Improve prevention of environmentally related cancers.

Objective 1:

Improve cancer prevention program evaluation.

Objective 2:

Improve data collection and carcinogen exposure assessment.

Objective 3:

Improve information regarding occupational risk factors for cancer.

Objective 4:

Enhance collaboration between academic research institutions and state and local public health departments.

Objective 5:

Improve recognition and screening for cancers associated with infectious agents.

Objective 6:

Reduce the differences in cancer rates attributable to socioeconomic status or racial status.

Chapter 9: Colorectal Cancer

Goals:

Reduce colorectal cancer mortality.

Reduce disparities in the incidence and mortality of colorectal cancer.

Objective 1:

Increase the rate of screening for colorectal cancer of those aged 50 and older by increasing the public's knowledge of colorectal cancer risk factors, symptoms, screening recommendations, and options.

Objective 2:

Clarify myths and dispel fears about colorectal cancer related to appropriate screening and prevention methods.

Objective 3:

Increase the knowledge of primary care providers (including family physicians, internists, and gynecologists) of appropriate colorectal cancer screening recommendations, and increase the proportion of providers who recommend or provide screening for colorectal cancer.

Objective 4:

Increase the trust of the public in the health care system.

Objective 5:

Promote health insurance coverage for colorectal cancer screening methods that are appropriate for each individual.

Objective 6:

Overcome barriers to screening, including difficult pre-procedure colonic preparation, transportation issues, scheduling and timing issues including conflict with work schedules, living alone, etc.



Chapter 10: Breast Cancer

Objective 7:

Ensure that patients with insurance coverage for colorectal cancer screening are screened.

Objective 8:

Increase available funding to pay for diagnosis and treatment for all who are screened and found to need additional care.

Objective 9:

Overcome language, literacy, and cultural barriers in health care providers' offices.

Objective 10:

Increase funding for colorectal cancer screening among uninsured, low-income Maryland residents, especially in Baltimore City.

Objective 11:

Ensure that there are sufficient providers to perform colonoscopy and/or sigmoidoscopy for all who require the procedures in Maryland.

Objective 12:

Ensure that there are sufficient providers who can perform initial physicals and clearance examinations for the uninsured, accept low-income clients and clients with Medicare and Medical Assistance, and have flexible hours necessary to working patients.

Objective 13:

Communicate the importance of primary prevention of colorectal cancer through healthy lifestyles.

Goals:

Reduce the incidence of breast cancer in Maryland.

By 2008, reduce the proportion of late stage breast cancers diagnosed in all women and reduce the rates of late diagnosis in African-American women to that of white women.

Ensure that all women who develop breast cancer are diagnosed with Stage 1 disease with <1 cm tumors.

Research factors contributing to high incidence and mortality rates in Maryland and develop appropriate interventions.

Ensure access to prevention, screening, treatment, and follow-up care for all Maryland residents.

Preserve the Cigarette Restitution Fund (CRF) for addressing health issues in Maryland.

Objective 1:

Determine why Maryland has high breast cancer incidence and mortality rates compared to other states in the nation.

Objective 2:

Continue to monitor breast cancer prevention research and promote activities to prevent breast cancer.

Objective 3:

Increase breast cancer risk assessment and risk-appropriate strategies.

Objective 4:

Ensure continued access to early detection and treatment of breast cancer.

Objective 5:

Increase the number of providers that perform minimally invasive biopsy techniques.



Chapter 10: **Breast Cancer** *continued*

Objective 6:

Promote optimum state-of-the art breast cancer care for all breast cancer patients regardless of regional, racial, age, or other disparities.

Objective 7:

Increase the number of individuals with ductal carcinoma in situ and early stage breast cancer that receive treatment appropriate for their diagnosis.

Objective 8:

Provide breast cancer survivors with information regarding the long-term effects of treatment.

Chapter 11: **Prostate Cancer**

Goals:

Reduce prostate cancer mortality.

Reduce disparities in the mortality of prostate cancer.

Monitor the proportion of men who have had a PSA test and a digital rectal examination.

Objective 1:

Increase public education about prostate cancer.

Objective 2:

Continue to monitor research findings regarding the effectiveness of primary and secondary prevention interventions in reducing prostate cancer mortality.

Objective 3:

Promote informed decisionmaking prior to screening with PSA and digital rectal examination.

Objective 4:

Promote education about prostate cancer treatment and support services for patients diagnosed with prostate cancer.

Objective 5:

Monitor research in primary, secondary, and tertiary prevention.



Chapter 12: Oral Cancer

Goals:

Reduce oral cancer mortality.

Reduce disparities in the incidence and mortality of oral cancer.

Objective 1:

Increase oral cancer literacy among Marylanders.

Objective 2:

Increase provider education and training related to oral cancer prevention and early detection.

Objective 3:

Increase public access to oral cancer prevention, early detection, and treatment services.

Objective 4:

Increase scientific knowledge regarding oral cancer.

Objective 5:

Maintain a centralized, statewide mechanism for support of oral cancer initiatives.

Chapter 13: Cervical Cancer

Goal:

Reduce cervical cancer mortality in Maryland.

Objective 1:

Increase awareness in the general public of cervical cancer screening recommendations and availability of programs.

Objective 2:

Increase cervical cancer screening in women who have not been screened in the last five years, especially older women, and increase compliance with recommended follow-up.

Objective 3:

Ensure that all providers have access to state-of-the-art guidelines for the management of cervical abnormalities.

Objective 4:

Ensure access to medical care for all.

Objective 5:

Conduct Maryland-specific surveillance research on barriers to cervical cancer detection and treatment by establishing a statewide follow-back study mechanism to allow for monitoring of failures through follow-back and to evaluate and modify intervention strategies.

Objective 6:

Determine why there are discrepancies in survival among different segments of the state population, taking into account multiple factors including race and age.



Chapter 14: Pain Management

Goal:

Increase awareness of, and access to, comprehensive pain assessment and management services for all cancer patients in Maryland in light of the current public health crisis of inadequate pain control.

Objective 1:

Increase provider awareness and training regarding appropriate pain assessment, management, and relevant regulatory issues.

Objective 2:

Increase provider reimbursement for cancer pain therapies.

Objective 3:

Increase consistency among different health care systems regarding compliance and adherence to standards for cancer pain assessment and management.

Objective 4:

Eliminate barriers due to cultural, age, sex, and income disparities and ensure equal access to pain management therapies within the health care system.

Objective 5:

Increase scientific knowledge regarding assessment and treatment of cancer pain.

Objective 6:

Increase public knowledge and awareness of cancer pain management practices and referral sources.

Objective 7:

Enhance existing legislation and create new regulations designed to increase awareness of, and access to, comprehensive cancer pain assessment and management services for all cancer patients in Maryland.

Chapter 15: End-of-Life Care

Goal:

Increase the number of Maryland cancer patients, as well as their family members and friends, receiving quality end-of-life care and related services.

Objective 1:

Expand provider education and training related to end-of-life care.

Objective 2:

Increase public awareness of end-of-life issues.

Objective 3:

Improve access to end-of-life care for all Marylanders with specific attention to improving physician reimbursement for appropriate end-of-life care.

Objective 4:

Enhance access to the continuum of end-of-life care services throughout the state.

Objective 5:

Enhance scientific research into all aspects of end-of-life care.

PREFACE

Background

In 1994, the Centers for Disease Control and Prevention (CDC) worked with state cancer control staff throughout the nation and other cancer organizations to define the concept of comprehensive cancer control. CDC has defined comprehensive cancer control as “an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation.” Comprehensive cancer control is an emerging model that integrates a range of cancer control activities to maximize the use of limited resources to achieve desired cancer prevention and control outcomes. In 2003, the CDC provided funding for 12 states to develop comprehensive cancer control plans. Sixteen states have current comprehensive cancer control plans. The principles governing comprehensive cancer control are shown in Table 1.

Past Maryland Cancer Plans

In 1988, the Maryland Department of Health & Mental Hygiene (DHMH) received a cooperative agreement from the National Cancer Institute entitled “Data-Based Interventions in Cancer Control.” This cooperative agreement provided funds to DHMH to gather and analyze data on the burden of cancer in Maryland, develop a statewide cancer control plan, and implement one strategy identified in the plan.

As a result of this cooperative agreement, the first Maryland Cancer Control Plan was published in 1991. This plan represented a collaborative effort among several different offices within DHMH as well as community and academic organizations in the state. The priorities of this plan were the prevention and cessation of tobacco use and the early detection and treatment of breast and cervical cancer. Because of the priorities enumerated in the 1991 Maryland Cancer Control Plan, a statewide breast cancer screening program was initiated in cooperation with 26 community hospitals,

Table 1.
Comprehensive Cancer Control Principles

- Scientific data and research are used systematically to identify priorities and inform decision-making.
- The full scope of cancer care is addressed, ranging from primary prevention to early detection and treatment to end-of-life issues.
- Many stakeholders are engaged in cancer prevention and control, including the medical and public health communities, voluntary agencies, insurers, businesses, survivors, government, academia, and advocates.
- All cancer-related programs and activities are coordinated, thereby creating integrated activities and fostering leadership.
- The activities of many disciplines are integrated. Appropriate disciplines include administration, basic and applied research, evaluation, health education, program development, public policy, surveillance, clinical services, and health communications.

and a state-funded breast and cervical cancer diagnosis and treatment program was initiated for uninsured and underinsured, low income, non-Medical Assistance eligible Maryland residents. Subsequently, DHMH was awarded a multi-year cooperative agreement from the CDC to develop a statewide breast and cervical cancer screening program.

In 1996, the Maryland Cancer Control Plan was updated. The priorities identified in the second edition of the Maryland Cancer Control Plan included the prevention and cessation of tobacco use and the early detection of colorectal, breast, and cervical cancer.

Cancer Control History in Maryland

In Maryland, there exists an atmosphere of support and commitment to reduce cancer incidence and mortality rates and the suffering caused by cancer. The governor's office established the State Council on Cancer Control by an executive order on June 26, 1991 and updated this executive order in November 1997 and December 2002. Since the formation of the Maryland State Council on Cancer Control, Maryland has experienced an unprecedented period of partnership among the Maryland legislature, local health departments, and the major academic cancer centers.

The Maryland General Assembly has passed several laws related to cancer control that benefit residents. For example, in 1991, the Maryland General Assembly passed a law requiring Maryland health insurers to provide a benefit covering the cost of mammography screening. Since then the Maryland General Assembly has passed legislation on mandated benefits for colorectal cancer screening, prostate cancer screening, and laws to cover the cost of clinical trials.

With funds derived from the November 1998 Master Tobacco Settlement Agreement with the tobacco industry, the Maryland General Assembly created the Cigarette Restitution Fund (CRF) as the repository of all settlement funds received by Maryland. In the spring of 2000, the Maryland General Assembly crafted and then enacted SB 896 and HB 1425 creating the Cigarette Restitution Fund Program (CRFP) to implement strategies to conquer cancer and end smoking in Maryland.

As a direct result of the CRFP, Maryland has a strong, statewide network of cancer and tobacco community health coalitions that are comprised of individuals and organizations that are committed to addressing the cancer and tobacco-use prevention needs of local communities.

In addition, there are numerous and varied cancer prevention, education, and screening programs, cancer research programs, and tobacco-use prevention and cessation programs.

Development Process

The planning stage of the comprehensive cancer plan was initiated with a leadership institute sponsored by the CDC and the American Cancer Society (ACS). Representatives from the Maryland State Council on Cancer Control, University of Maryland School of Medicine, and ACS attended the leadership institute and met several times to discuss initial planning strategies. A Core Planning Team (CPT) was formed in April 2001 and included representatives from the Maryland DHMH, ACS, University of Maryland, Johns Hopkins University, and local health departments. The CPT developed a grant application for funding from CDC to develop a comprehensive cancer plan. In October 2001, DHMH was awarded a cooperative agreement from CDC, on behalf of the CPT, to develop a comprehensive cancer plan.

The membership of the CPT was then expanded to include representation from other nonprofit, health care, and community organizations from around the state. The overarching goal was to have broad representation within a small practical group that could reach consensus and make efficient decisions. The purpose of the CPT was to provide oversight and guidance to the development of an updated Maryland Comprehensive Cancer Control Plan.

Among its many activities, the CPT developed the overall framework in which the plan would be developed, drafted the outline of chapters to be included in the plan, determined the committees that would be formed, and assisted with recruiting membership for each committee. The CPT has continued to meet on an ongoing basis to provide direction to the development of the plan.

Committee Structure

The cancer control planning process in Maryland involved the establishment of working committees to focus on individual cancer topics and generate recommendations for cancer control within those respective topics. Several considerations were made during the recruitment process for committee members. First, the aim was to fill the committees with approximately 10–20 members each. It was agreed that committees larger than 20 members may have difficulty meeting

deadlines and obtaining consensus and that committees with fewer than 10 members would provide inadequate input. Second, it was vital that committee members be diverse, balanced, and include the necessary scientific expertise relevant to the committee's topic. Special efforts were made to recruit minorities as well as appropriate professionals, including epidemiologists and health care providers.

Committee members were recruited from DHMH, local health departments, other government agencies, community-based organizations, hospitals and other health care facilities, advocacy organizations, cancer support groups and survivor networks, and the two largest academic centers in Maryland (Johns Hopkins University and the University of Maryland). Individual recruitment was then conducted as needed to maintain balance and diversity in membership. A total of over 200 individuals were recruited to serve on the 14 committees. Members of each committee, as well as guest speakers and chapter contributors, are listed at the beginning of each chapter in this plan.

A chairperson was selected for each of the 14 committees. DHMH staff worked closely with each chairperson to develop agendas, timelines, and materials for committee meetings and to coordinate operational matters for each committee. Over the course of several meetings, the committees reviewed materials and employed a variety of methods to accomplish their goal, which was to develop a set of recommendations that would form the basis of the corresponding chapter in the new cancer plan. Most committees dedicated one or more meetings to the review of epidemiologic data and scientific literature and to the compilation and assessment of information on current programs and policies. The committees utilized topical brainstorming and the nominal group process to generate and prioritize ideas, ultimately drafting a list of strategies for inclusion in their corresponding chapter.

Town Hall Meetings

In an effort to gain public input for the 2004–2008 Maryland Comprehensive Cancer Control Plan, a series of seven public town hall meetings were held across the state between July 16 and August 8, 2002. The details of the meetings are shown in Table 2.

A staff person facilitated each meeting and panelists consisted of members of the Maryland State Council on Cancer Control, the CPT, and the working committees. On the Eastern Shore, two sites incorporated

the use of video-conferencing technology.

Over 170 people participated in the town hall meetings and provided input on the cancer issues faced by Marylanders. Testimony was compiled for each meeting and organized by subject area to correspond with the 14 committee topics. Relevant testimony was then returned to each committee for review and incorporation into their recommendations. A complete summary of proceedings of the town hall meetings is available on the cancer plan website at <http://www.marylandcancerplan.org/meetings.html>.

Consensus Conference

A statewide consensus conference was held on October 16, 2002 and, with over 300 people in attendance, served as the first public forum for the 14 committees to present their preliminary findings and recommendations. The two main goals of the conference were (1) to share the accomplishments of the 14 working committees and (2) to provide an arena for public comment on the recommendations of the committees and to serve as another venue for public involvement in the development of the new cancer plan.

Participants were asked to complete a feedback packet, which allowed for comment on specific content areas of each presentation. Feedback was then compiled and given to each committee chairperson and/or chapter writer for consideration. Each of the PowerPoint presentations, as well as complete transcripts of the feedback submitted by participants, is available on the cancer plan website at <http://www.marylandcancerplan.org/presentations.html>.

Writing Phase

Writing of the cancer plan commenced in early 2003 after the committees reviewed the feedback from the consensus conference. After all committee meetings were complete, a chapter writer was recruited from the membership of the committee. In some instances multiple writers were recruited for a chapter. Detailed chapter outlines for each chapter were developed by DHMH staff and provided to all chapter writers as a means to facilitate the writing process. A committee review process was conducted for all chapters in this cancer plan. Committee members were provided with a draft chapter and were asked to submit comments and suggestions regarding the content and structure of the document. Editorial, design, and layout services were performed by Evins Design of Baltimore, MD.

Table 2
Maryland Regions Served by the 2002 Town Hall Meetings

Date	Location	Region Served
July 16 6:00–8:00 p.m.	Prince George's Hospital Center, Cheverly, MD	Prince George's County
July 18 6:00–8:00 p.m.	Anne Arundel County Public Library Linthicum, MD	Central Maryland
July 25 6:00–8:00 p.m.	Charles County Health Department White Plains, MD	Southern Maryland
July 30 6:00–8:00 p.m.	American Cancer Society Silver Spring, MD	Montgomery County
August 1 6:00–8:00 p.m.	Bon Secours Baltimore Health System Baltimore, MD	Baltimore City
August 6 4:00–6:00 p.m.	Robinwood Medical Center Hagerstown, MD	Western Maryland
August 8 4:00–6:00 p.m.	Eastern Shore Oncology Regional Cancer Center Easton, MD University of Maryland, Statewide Health Network Salisbury, MD	Eastern Shore

Evaluation of the Planning Process

An evaluation committee consisting of members of the CPT was formed to monitor the evaluation component of the cancer control plan development process. The evaluation committee chose the Content-Input-Process-Product model (CIPP) as the basis for evaluating the planning process and adapted the model for use in Maryland. Use of the CIPP model facilitates analysis of information and data so that modifications can be considered, alternatives examined, and final decisions made. Evaluation was accomplished through a continuous and systematic approach of feedback acquisition at each committee meeting for the purpose of modifying the planning process as needed.

Website

The cancer plan website (<http://www.marylandcancerplan.org>) was an invaluable communication tool throughout the planning process. The website allowed for quick and easy information dissemination to those participating in the planning process, including announcements about upcoming meetings, event information and registration, and planning updates. In addition, the website provided the comprehensive cancer planning process in Maryland with an elevated public profile and provided access to a broad audience. Through the availability of a variety of electronic forms, the website allowed input and participation from many individuals not directly involved in cancer control in Maryland. The website will serve as the online home for the cancer plan as well as the future home for information related to the implementation process.

CHAPTER 1

BURDEN OF CANCER IN MARYLAND

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BURDEN OF CANCER IN MARYLAND

Cancer is the second leading cause of death in Maryland after heart disease and one in four deaths in Maryland are due to cancer (Table 1.1). Improvements in the prevention, early detection, and treatment of many types of cancer have led to a decline in the overall cancer death rate in Maryland and the nation.¹ Cancer mortality rates in Maryland had been increasing until 1990 when the mortality rates started to

fall. Cancer mortality rates are falling across all sexes and races in Maryland (Figure 1.1).

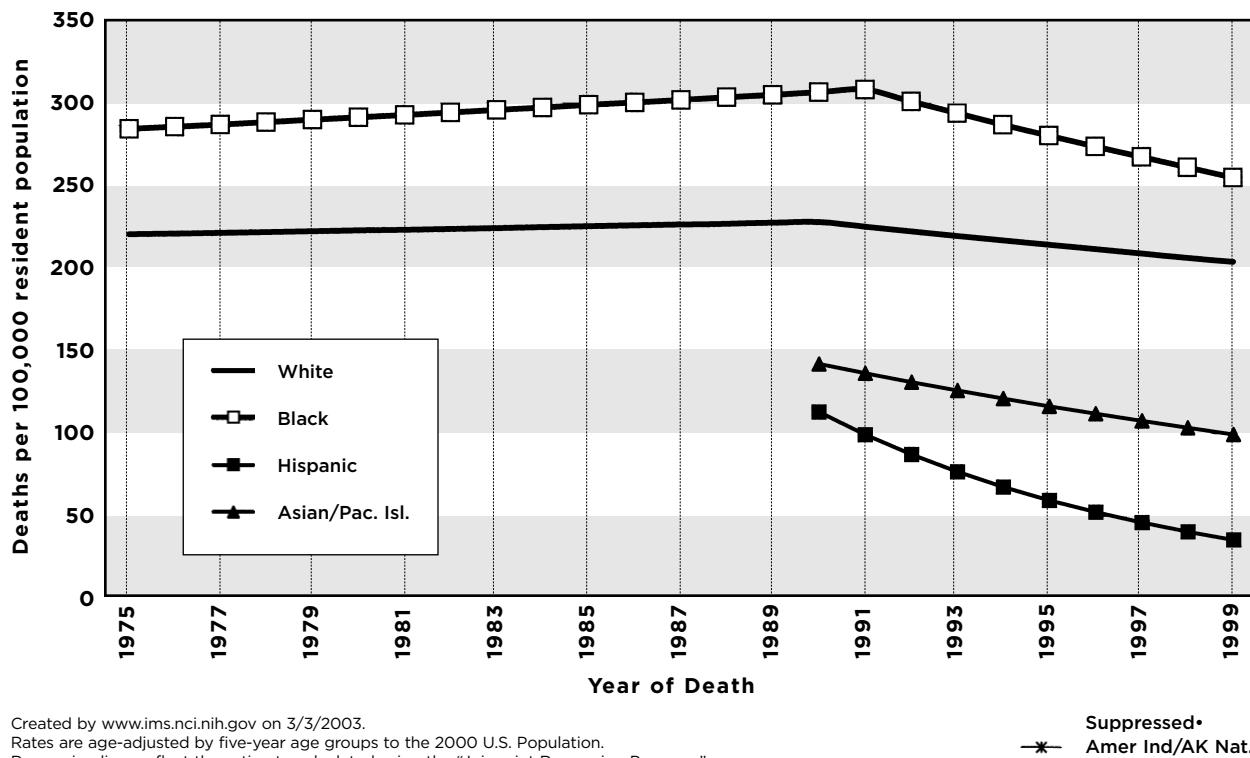
Despite these declines, the burden of cancer in Maryland remains formidable. The population in Maryland is aging and becoming demographically more diverse. Because cancer occurs more often in older persons, the burden of cancer is expected to grow. The total annual number of cancer cases and the number of persons living with cancer in the United States are expected to double by the year 2050.² The increased number of persons living with cancer will place a growing demand on the health care system for more supportive, palliative, and general medical services. A focus on the quality of life of cancer survivors will become more important as more

Table 1.1
The Seven Leading Causes of Death in Maryland, 1999

Rank	Cause of Death	Number of Deaths	Percent of Total Deaths
	All Causes	42,908	
1	Heart disease	12,014	28.0%
2	Cancer	10,096	23.5%
3	Cerebrovascular disease	2,860	6.7%
4	Chronic respiratory disease	1,941	4.5%
5	Diabetes	1,408	3.3%
6	Accidents	1,240	2.9%
7	Influenza and pneumonia	1,150	2.7%

Rates are per 100,000 population and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Vital Statistics, Annual Report, 1999; Maryland Cancer Registry, 1999.

Figure 1.1
Historical Trends in Cancer Mortality in Maryland for All Cancer Sites, Both Sexes, and All Ages (1975-1999)



and more persons are surviving cancer.^{3,4}

The demographic makeup of Maryland's population continues to diversify. Overall, blacks suffer a disproportionately higher burden of cancer compared to whites. The Hispanic population in the state is growing, as are other minority populations. There is a need to better understand the magnitude of cancer incidence, survival, mortality, and the issues faced by these racial and ethnic groups, including access to care and a greater need for culturally appropriate prevention, early detection, and treatment. Not all segments of the population have benefited equally from cancer prevention and treatment control efforts; more efforts are needed to overcome health disparities. These efforts will require greater attention to education, costs, access, and cultural appropriateness.⁵

Advances in emerging cancer control technologies and the application of effective interventions, as well as improved access to state-of-the-art cancer care, should lead to further reductions in cancer death rates. However, even with these improvements, the aging of the population alone will increase the number of persons who are diagnosed with and treated for cancer,

and who will survive longer at increasingly older ages.⁶ The overall goals for this plan are to decrease overall cancer mortality, decrease overall cancer incidence, improve the quality of life for all cancer survivors, and reduce cancer disparities among ethnic minorities.

Cancer Mortality (Deaths)

Over 10,000 Marylanders die from cancer each year. Maryland's overall cancer mortality rate of 211.7 deaths per 100,000 population in 1999 was statistically significantly higher than the 1999 U.S. cancer mortality rate of 202.8 deaths per 100,000 population (Table 1.2).

Maryland's rank in overall cancer mortality rates has been steadily improving compared to other states in the nation and the District of Columbia. For the time period 1986–1990, Maryland had the third highest cancer mortality rate in the nation; for the time period 1991–1995, Maryland ranked 6th highest; and for the time period 1996–2000, Maryland's rank dropped to the 11th highest cancer mortality rate in the nation.⁷

Table 1.2
Overall Cancer Incidence and Mortality by Sex and Race
in Maryland and the United States, 1999

Incidence 1999	Total	Males	Females	Whites	Blacks	Other
New cases (#)	23,267	11,964	11,300	17,313	4,807	592
Incidence rate	476.8	569.3	414.8	469.7	468.1	370.2
U.S. SEER rate	476.1	555.8	422.3	478.3	519.1	N/A
Mortality	Total	Males	Females	Whites	Blacks	Other
MD Deaths (#)	10,096	5,208	4,888	7,560	2,394	142
MD Mortality rate	211.7	266.2	177.3	204.0	257.9	105.1
U.S. Mortality rate	202.8	252.6	169.6	199.8	256.5	N/A

Rates are per 100,000 population and are age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

Cancer mortality increases with age for all races and sexes (Figure 1.2).

Overall cancer mortality rates are higher in males than females, with black males having the highest overall cancer mortality rate. Black males have higher mortality rates than white males, and black females have higher overall cancer mortality rates than white females in Maryland (Figure 1.3).

Although cancer occurs more frequently with advancing age, it is also the second leading cause of death in children aged 5–14 years and the leading cause of death in adults aged 25–64 years (Table 1.3).

Overall cancer mortality rates from 1995 to 1999 were statistically higher than the U.S. in 12 Maryland jurisdictions (Anne Arundel, Baltimore, Baltimore City, Caroline, Cecil, Charles, Dorchester, Harford, Prince George's, Somerset, Wicomico, and Worcester counties), comparable to the U.S. in 10 jurisdictions (Allegany, Calvert, Carroll, Frederick, Howard, Kent, Queen Anne's, St. Mary's, Talbot, and Washington counties), and statistically lower than the U.S. in two jurisdictions (Garrett and Montgomery counties) (Figure 1.4).

There are over 100 different types of cancer that are classified according to the organ or tissue of origin and histologic features. Lung cancer is the leading cause of cancer deaths, accounting for almost one-third (28.6%) of all cancer deaths in Maryland. Colorectal cancer follows, accounting for 10.9% of all cancer deaths in the state. Breast cancer accounts for 8.3%

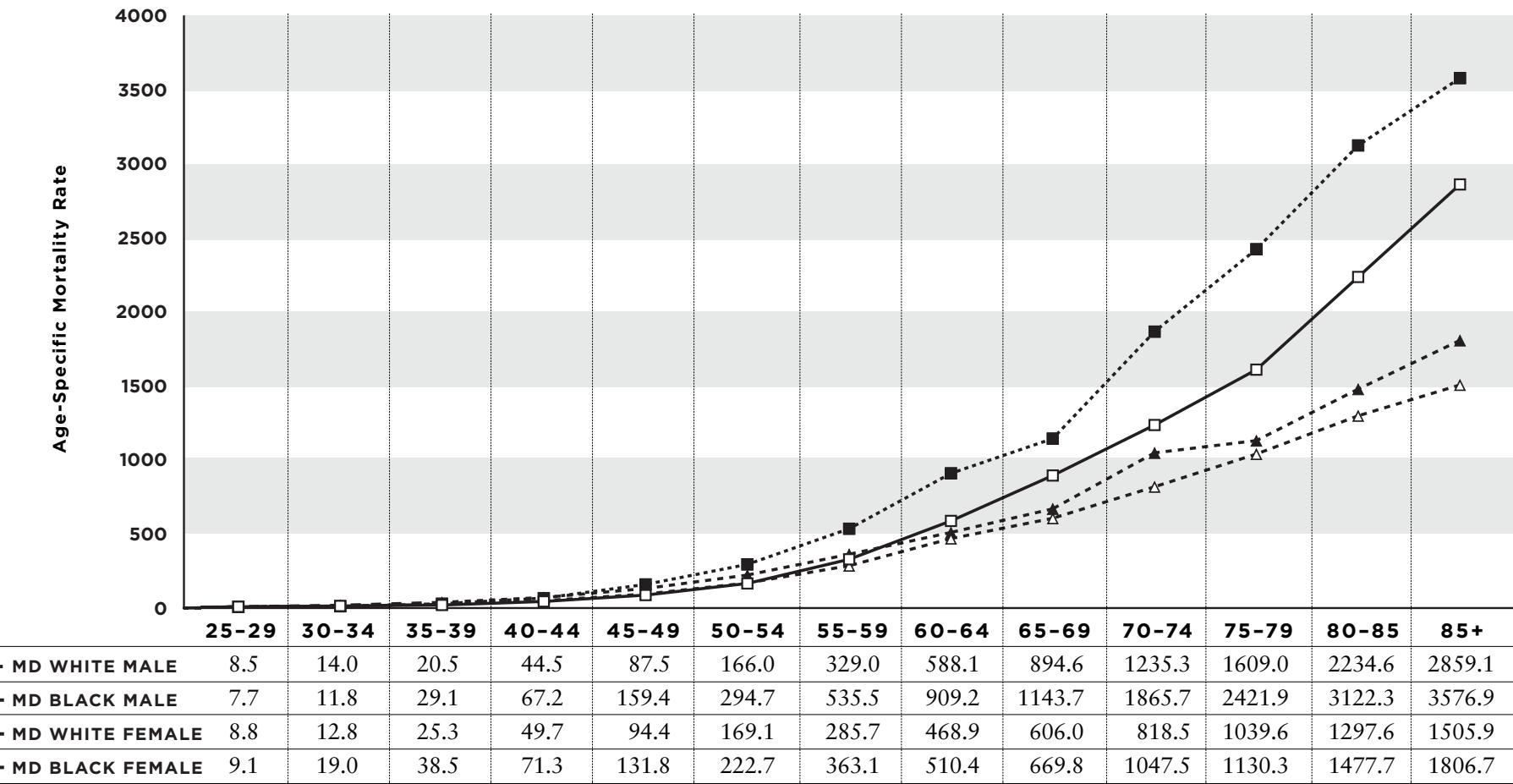
and prostate cancer accounts for 6.0% of all cancer deaths in Maryland. Together, cancers of the lung and bronchus, colon and rectum, breast, and prostate account for over half (53.8%) of deaths due to cancer in Maryland (Figure 1.5).

There have been notable trends in cancer mortality among different cancer sites in the last seventy years. In the United States, lung cancer became the leading cause of cancer death among males in the mid-1950s and the leading cause of cancer death among females by the late 1980s. Lung cancer mortality in Maryland has started to decrease among males, but, unfortunately, is still increasing in females. Lung cancer remains, by far, the leading cause of cancer deaths in both men and women (Figures 1.6 and 1.7). Any significant efforts to improve cancer mortality rates will need to address the primary causes of lung cancer, especially tobacco use among Marylanders.

Mortality due to the three most common cancer sites (colon and rectum, breast, and prostate) is decreasing overall in Maryland. From 1995 to 1999, Maryland experienced a decrease in cancer mortality rates for cancer overall, for these three major cancer sites, and among all races and both sexes. However, cancer mortality rates are increasing for leukemias and cancers of the bladder, corpus uterus, and pancreas (Figure 1.8).

Among Maryland men, the five leading causes of cancer deaths are cancers of the lung and bronchus, prostate, colon and rectum, pancreas, and non-Hodgkins lymphoma. Among Maryland women, the

Figure 1.2
All Sites Age-Specific and Cancer Mortality Rates by Race and Sex in Maryland, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

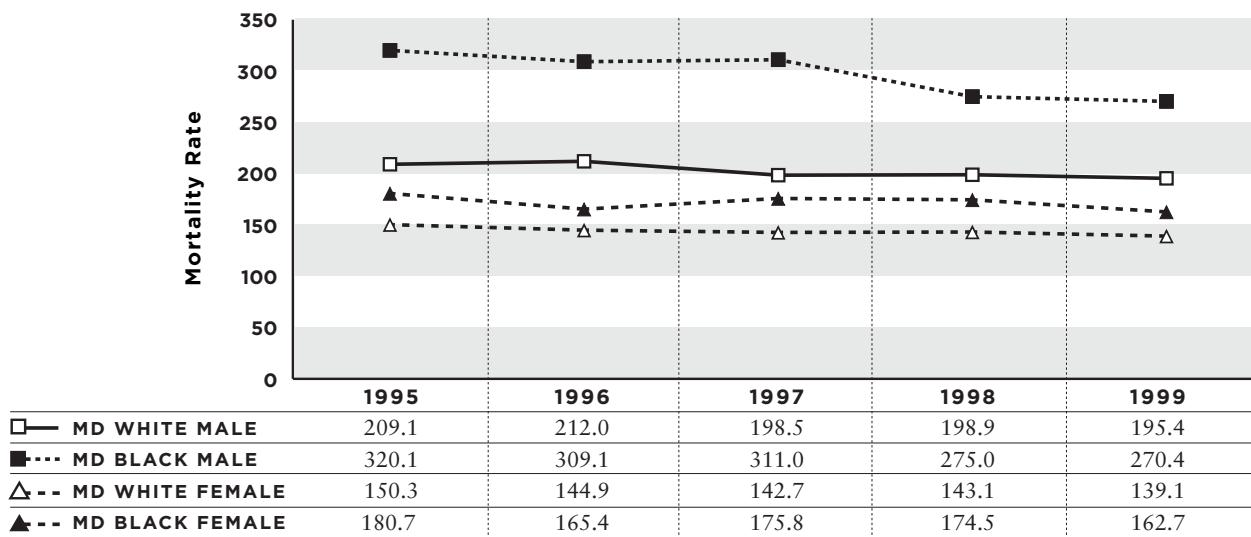
Source: Maryland Division of Health Statistics, 1995-1999.

Table 1.3
Leading Causes of Deaths by Age in Maryland, 1999

Age	Cause of Death	Number of Deaths	Percent of Deaths
5–14 years	Accidents	42	33.1%
	Cancer	21	16.5%
15–24 years	Assault	196	31.3%
	Accident	193	30.8 %
	Suicide	63	10.1%
25–44 years	Cancer	415	13.8%
	Human Immunodeficiency Virus (HIV)	369	12.3%
	Diseases of the heart	344	11.5%
45–64 years	Cancer	2,659	34.7%
	Diseases of the heart	1,879	24.5%
	Diabetes	299	3.9%
65 years & older	Diseases of the heart	9,727	31.6%
	Cancer	6,967	22.6%
	Cerebrovascular disease	2,521	8.2%

Source: Maryland Vital Statistics, Annual Report, 1999.

Figure 1.3
All Sites Cancer Mortality Rates by Race and Sex in Maryland, 1995–1999



Rates are per 100,000 population and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995–1999.

Figure 1.4
Overall Maryland Cancer Mortality Rates by Geographical Area:
A Comparison to Rates in the United States, 1995-1999

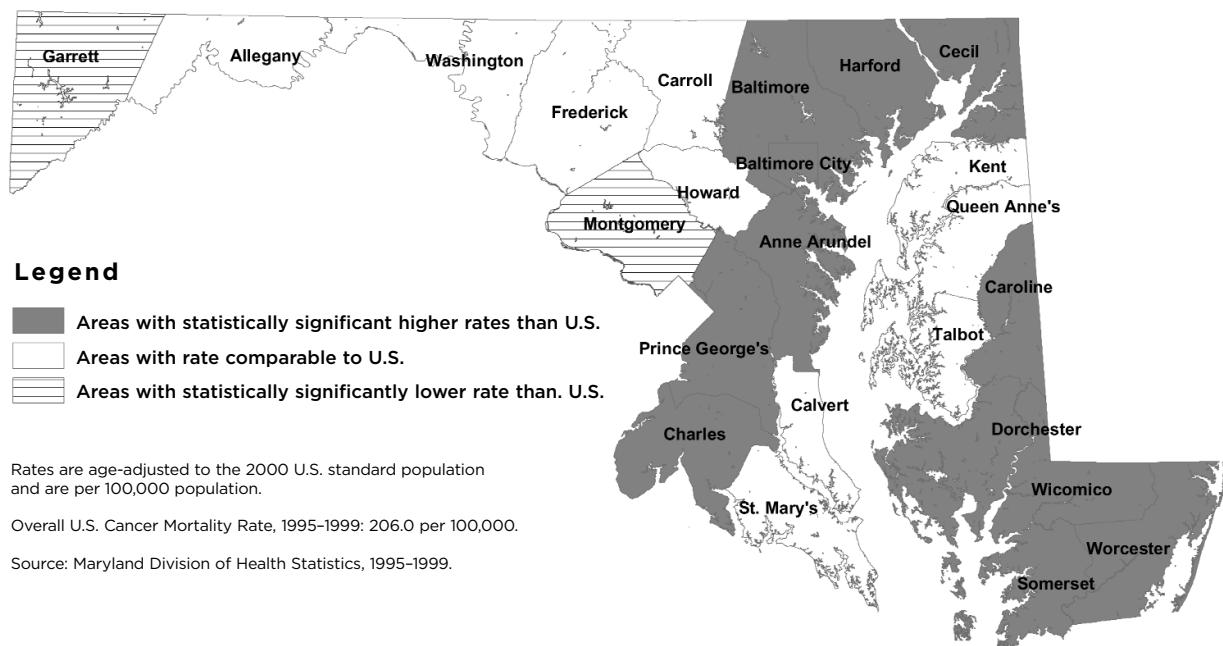
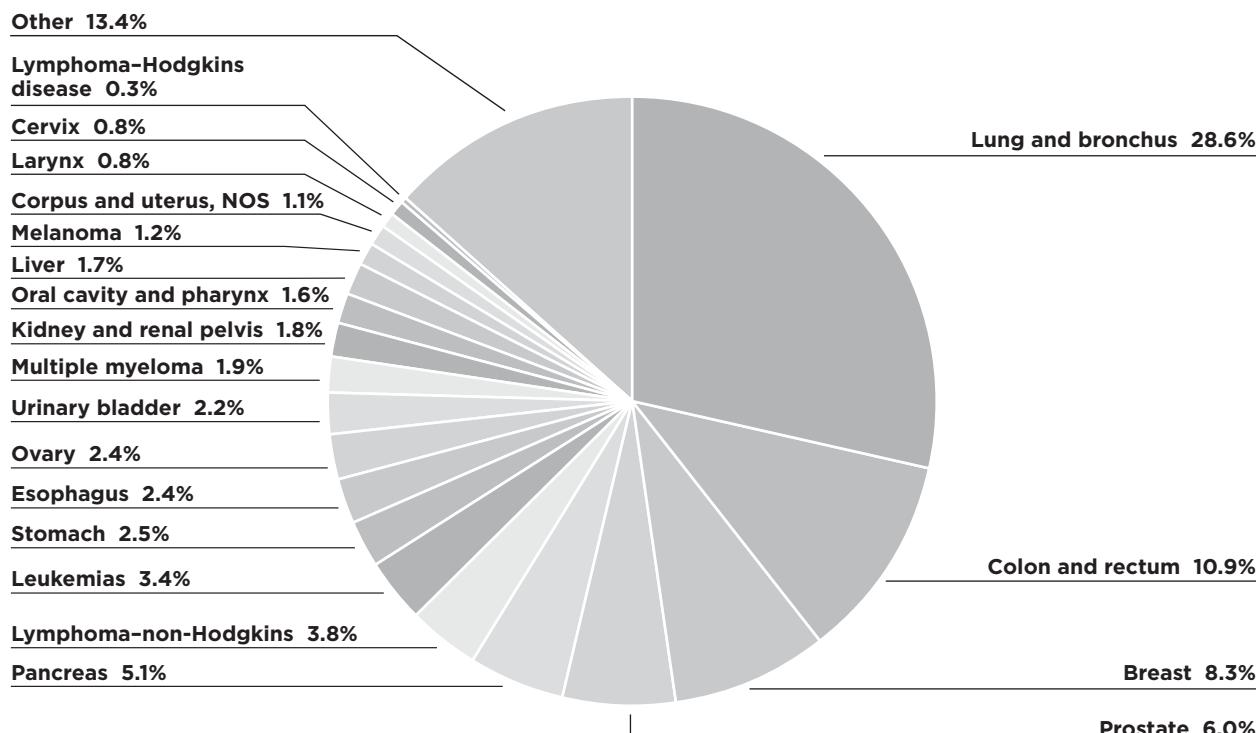
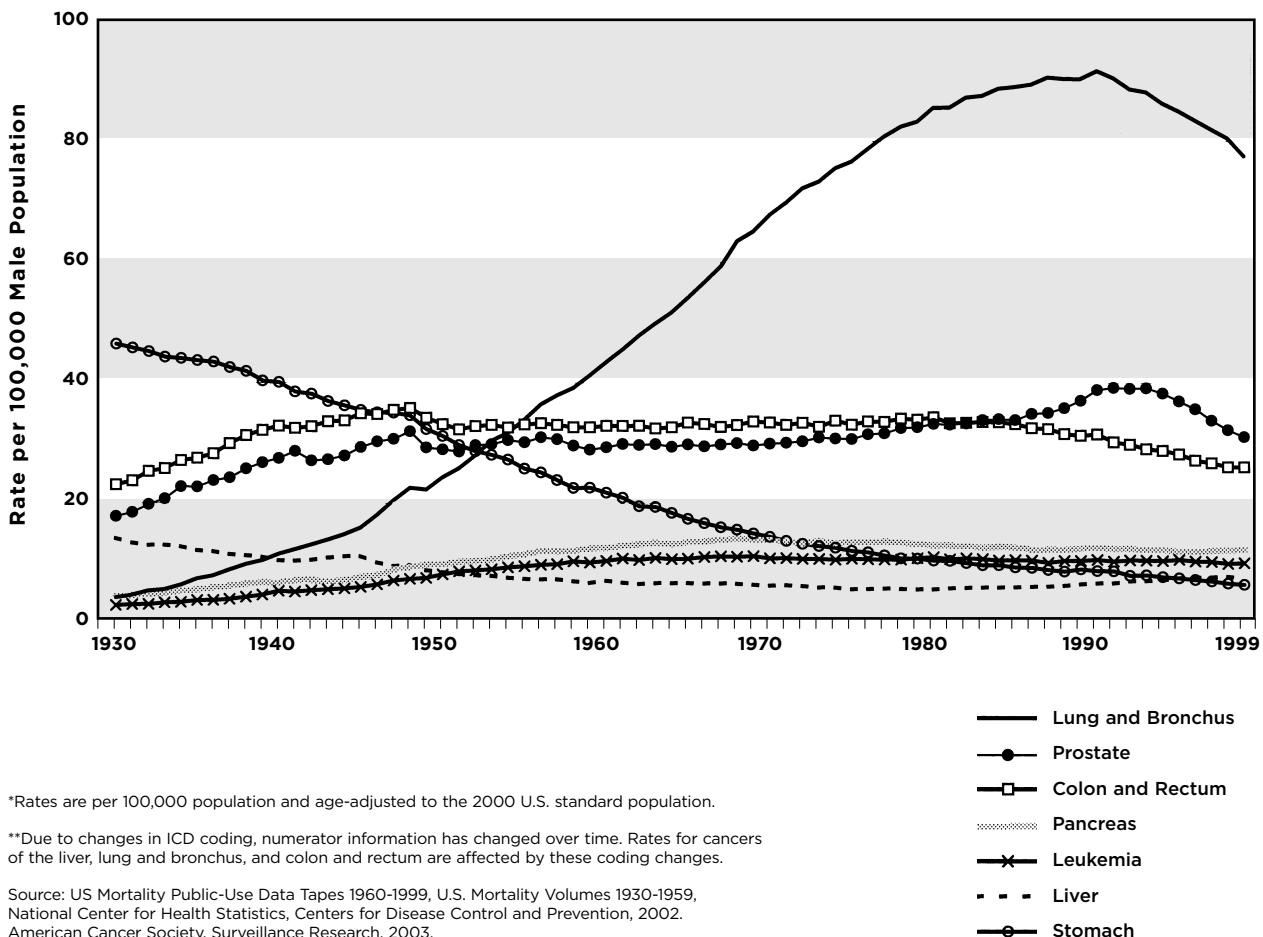


Figure 1.5
Percent of Cancer Deaths by Type of Cancer in Maryland, 1995-1999*



*Total deaths reported 1995-1999 = 50,694
 Source: Maryland Division of Health Statistics, 1995-1999.

Figure 1.6**Age-Adjusted Cancer Death Rates* of U.S. Males by Site, 1930-1999**

five leading causes of cancer death are cancers of the lung and bronchus, breast, colon and rectum, pancreas, and ovary (Table 1.4).

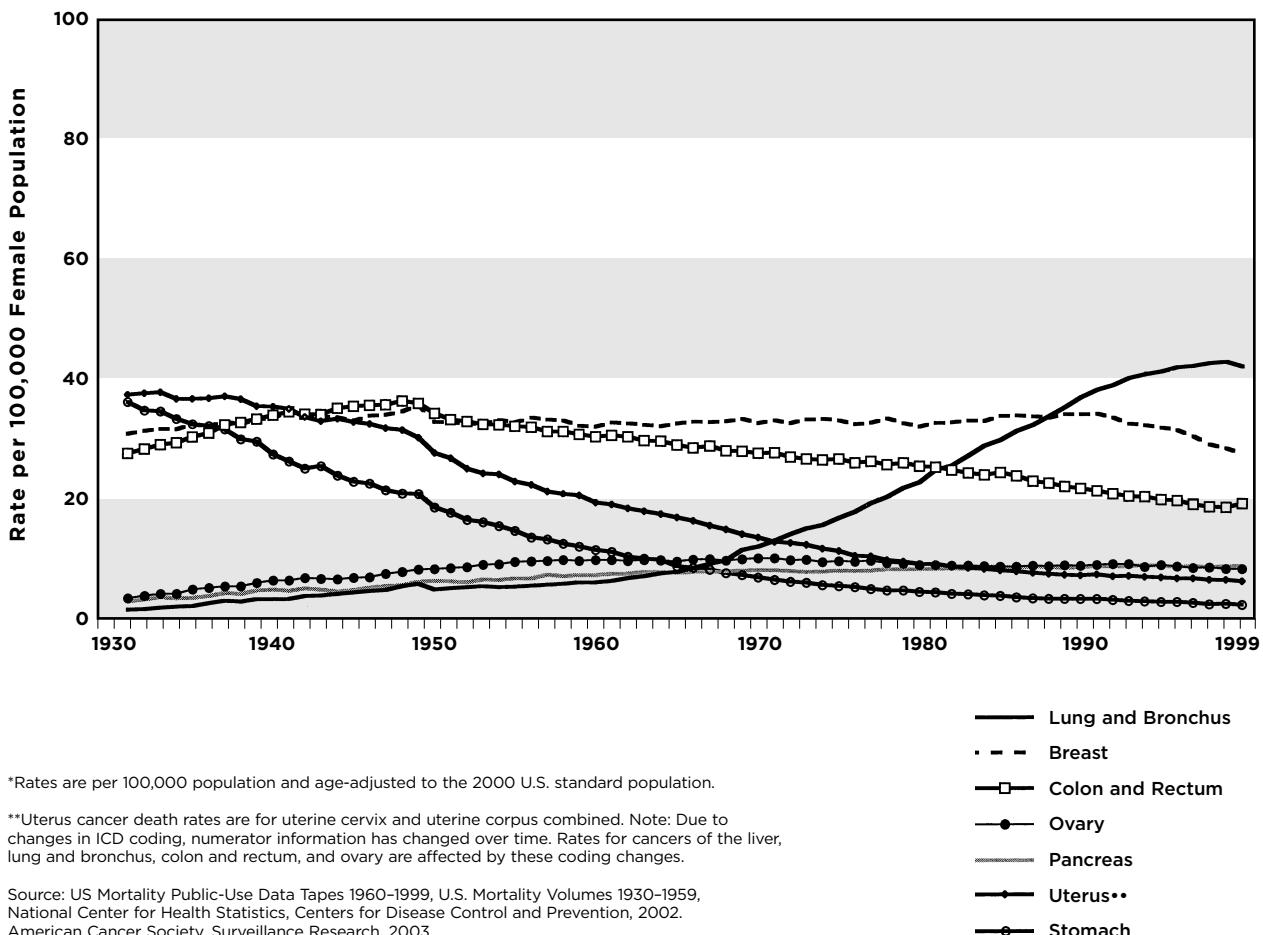
Cancer mortality varies by age. Leukemia, brain and central nervous cancers, and non-Hodgkins lymphoma are the most common causes of cancer deaths among children under 19 years of age; cancers of the lung and bronchus, breast, colon and rectum, pancreas, and non-Hodgkins lymphoma are the most common causes of cancer death among adults aged 20-49 in Maryland; and cancers of the lung, colon and rectum, breast, and prostate are the most common causes of cancer death among persons aged 50 and older in Maryland.

Cancer Incidence (New Cases)

Each year, over 23,000 Marylanders are diagnosed

with cancer. The age-adjusted cancer incidence rate for Maryland in 1999 of 476.8 cancer cases per 100,000 population is comparable to (i.e., not significantly different from) the 1999 U.S. SEER cancer incidence rate of 476.1 cancer cases per 100,000 population (Table 1.2). The overall age-adjusted cancer incidence rate for men in Maryland, however, is statistically significantly higher than the rate for men in the U.S. In addition, Maryland men have higher age-adjusted cancer incidence rates for lung and bronchus and prostate cancers compared to men in the U.S. The age-adjusted cancer incidence rate for Maryland females is comparable to the rate for females in the U.S.⁸

Total cancer incidence rates in Maryland decreased an average of 3.4% per year from 1995 to 1999.⁹ During this time period, overall cancer incidence rates declined in black men and white men, remained relatively stable in black females, and increased slightly in white females (Figure 1.9).

Figure 1.7**Age-Adjusted Cancer Death Rates* of U.S. Females by Site, 1930-1999**

Cancer occurs predominantly in older persons, with a median age at diagnosis of 68 years.¹⁰ Cancer incidence increases with age across all races and sexes. One in 12 males and 1 in 11 females aged 40–59 years of age will develop cancer, whereas 1 in 3 men and 1 in 5 women aged 60 to 79 years of age will develop cancer.¹¹ Cancer incidence rates are higher in males than females over age 54 in Maryland. Below the age of 50, white women have the highest cancer incidence rates (Figure 1.10).

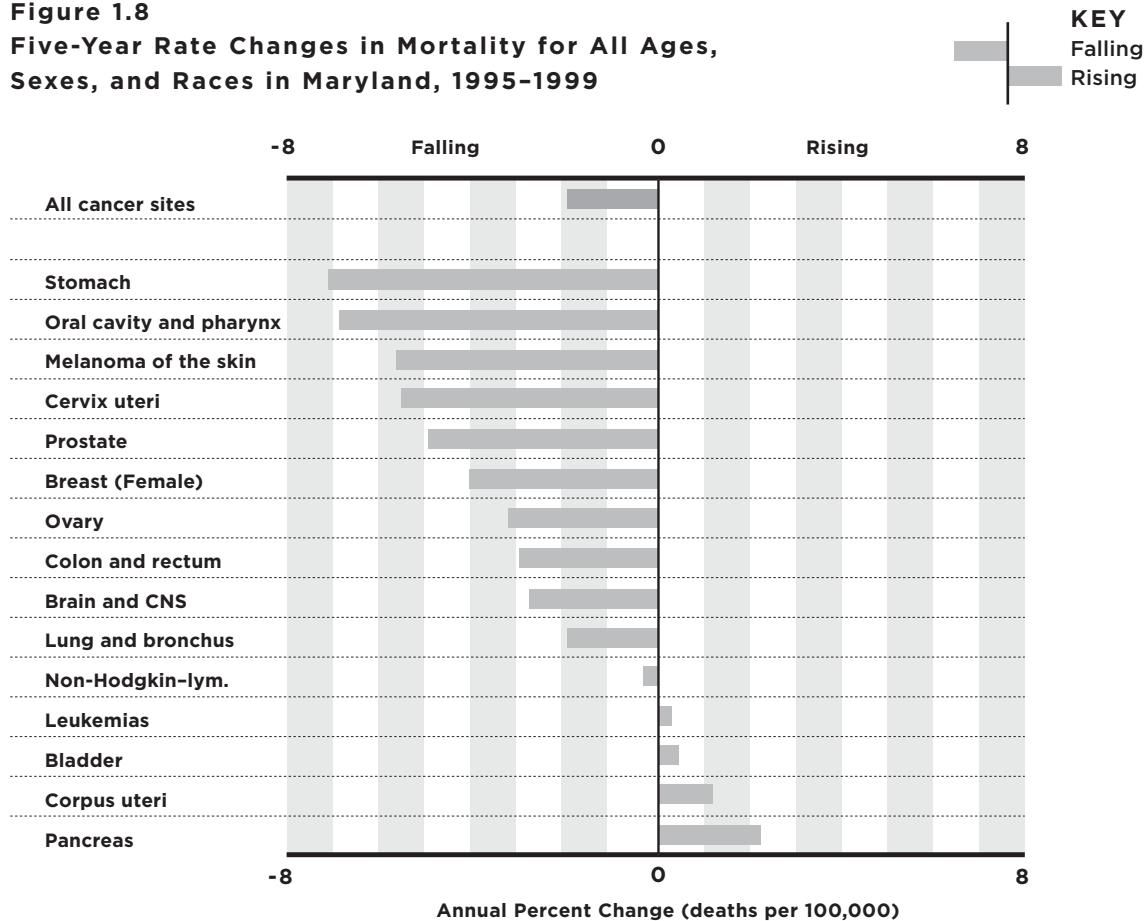
The most frequently diagnosed cancers among persons under 20 years of age differ from those occurring in older age groups. Leukemia and cancer of the brain and central nervous system account for approximately 37% of cancers among persons under the age of 20. Among persons aged 20–49 years, breast cancer incidence is substantially higher than any other cancer site, representing over 27% of all cancers diagnosed in this age group. Melanoma, lung and bronchus, thyroid, and colorectal cancer ranked high in frequency for this

age group after breast cancer. Among persons 50 years of age and older, prostate, lung and bronchus, breast, and colorectal cancer were the most frequently occurring cancers.

The most commonly diagnosed cancers among Marylanders are prostate (15.8%), breast (15.6%), lung and bronchus (15.1%), and colon and rectum (11.4%) cancers. Combined, these cancers comprise 57.98% of all cancers diagnosed (Figure 1.11).

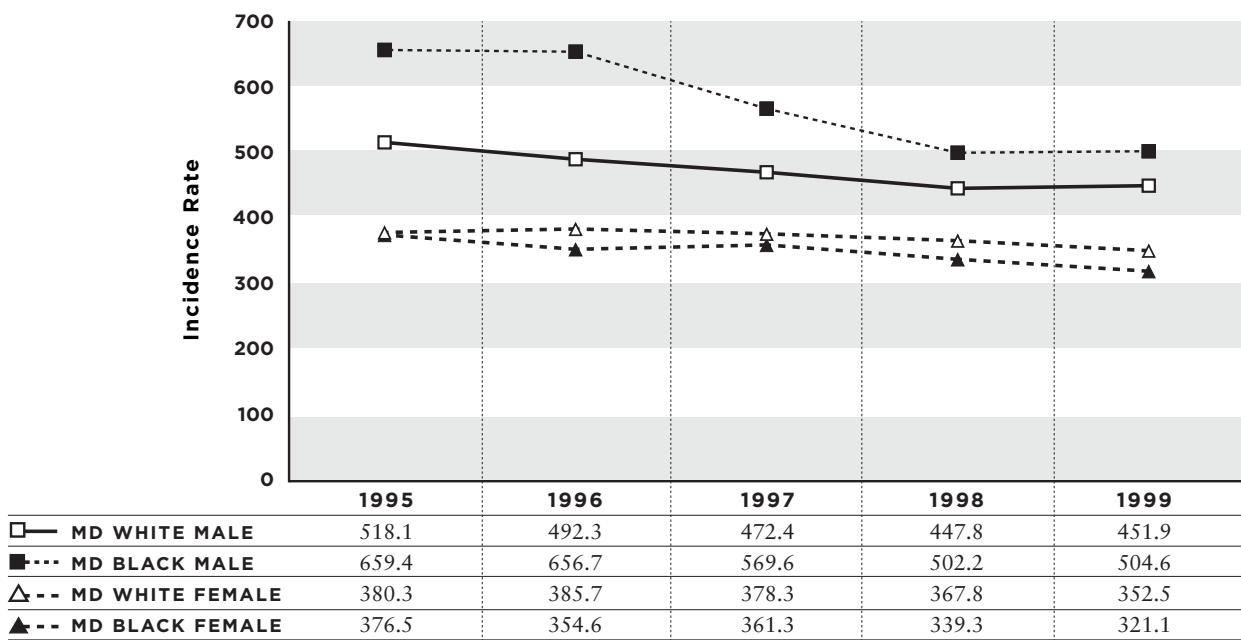
Among Maryland men, cancers of the prostate, lung and bronchus, and colon and rectum comprise over 58% of all newly diagnosed cancers. Among Maryland women, cancers of the breast, lung and bronchus, and colon and rectum comprise 57% of all newly diagnosed cancer cases. (Table 1.5).

Figure 1.8
**Five-Year Rate Changes in Mortality for All Ages,
 Sexes, and Races in Maryland, 1995-1999**



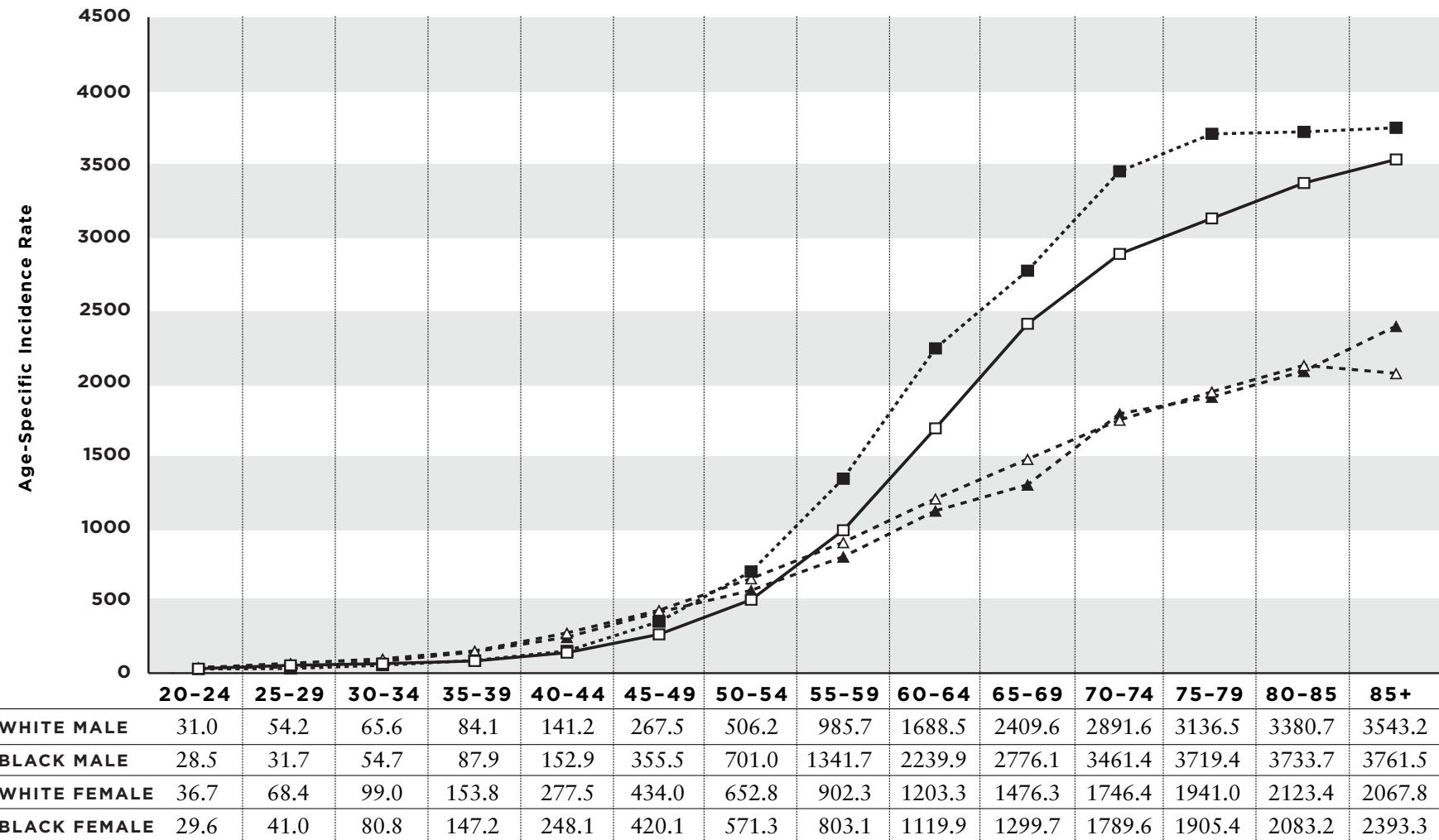
Created by www.ims.nci.gov on 02/04/2003.
 Trend: Five-year Annual Percent Change (APC) as calculated by SEER*Stat.
 Source: National Center for Health Statistics as analyzed by the National Cancer Institute.

Figure 1.9
All Sites Cancer Incidence Rates by Race and Sex in Maryland, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
 Source: Maryland Cancer Registry, 1995-1999.

Figure 1.10
All Sites and Age-Specific Cancer Incidence Rates by Race and Sex in Maryland, 1995-1999



Rates are per 100,000 population.

Source: Maryland Cancer Registry, 1995-1999.

Table 1.4
Five Leading Causes of Cancer Mortality in Maryland by Sex, 1995-1999

Cancer Site	MALES Percent of Deaths	FEMALES Cancer Site	Percent of Deaths
Lung and bronchus	32.2%	Lung and bronchus	24.8%
Prostate	11.7%	Breast	16.8%
Colon and rectum	10.4%	Colon and rectum	11.4%
Pancreas	4.8%	Pancreas	5.4%
Non-Hodgkins lymphoma	3.9%	Ovary	4.9%

Source: Maryland Cancer Registry, Maryland Vital Statistics, 1995-1999.

Table 1.5
Seven Leading Cancer Incident Sites by Sex in Maryland, 1995-1999

Cancer Site	MALES Percent of New Cases	FEMALES Cancer Site	Percent of New Cases
Prostate	30.9%	Breast	31.8%
Lung and bronchus	16.6%	Lung and bronchus	13.5%
Colon and rectum	11.0%	Colon and rectum	11.9%
Bladder	5.7%	Corpus uterus	5.0%
Non-Hodgkins lymphoma	3.7%	Ovary	3.6%
Melanoma of the skin	3.6%	Non-Hodgkins lymphoma	3.4%
Oral cavity	3.1%	Melanoma	2.9%

Source: Maryland Cancer Registry, DHMH, 1995-1999.

Table 1.6
Trends in Five-Year Relative Survival Rates by Year of Diagnosis in the United States, 1974 to 1998

Cancer Type	1974 to 1976	1983 to 1985	1992 to 1998
All cancers	50%	52%	62%
Lung and bronchus	12%	14%	15%
Colon cancer	50%	58%	62%
Rectum cancer	49%	55%	62%
Breast cancer	75%	78%	86%
Prostate cancer	67%	75%	97%

Source: American Cancer Society Facts and Figures, 2003.

Stage of Disease and Survival

Staging is the process of determining the extent of disease progression at the time of diagnosis. Blacks are less likely to be diagnosed with cancer at the localized stage, when the disease may be more easily and successfully treated, and more likely to be diagnosed at regional and distant stages.¹²

The five-year relative survival rate represents the proportion of persons who are living five years after a diagnosis of cancer. There have been notable improvements in U.S. five-year relative survival rates for the most common cancers. (Survival data is not available for Maryland.) Five-year relative survival rates for all cancers increased from 50% in 1974–1976 to 62% in 1992–1998 (Table 1.6). For nearly every cancer type, blacks have lower five-year relative survival rates than whites at each stage of diagnosis.¹³

Economic Impact: Costs for Cancer Care

The economic impact of cancer is large. The National Institutes of Health estimates that the overall cost for cancer in the year 2002 was \$171.6 billion, of which \$60.9 billion was for direct medical costs (i.e., the total of all health expenditures), \$15.5 billion was for indirect morbidity costs (i.e., the cost of lost productivity due to illness), and \$95.2 billion was for indirect mortality costs (i.e., the cost of lost productivity due to premature death). Maryland's population represents approximately 1.88% of the total U.S. population. Using this proportion of the national annual direct costs for cancer, it is estimated that the total annual cost for cancer in Maryland in the year 2002 was \$3.2 billion, and the total direct medical cost was \$1.1 billion (Table 1.7).

Risk Factors

Cancer can be attributed to a variety of factors. These factors may act together or in sequence to initiate or promote the development of cancerous cells.¹⁴ Various estimates have been made regarding the proportion of cancer deaths attributable to certain factors (Table 1.8). It is estimated that nearly two-thirds of cancer deaths in the United States can be linked to the use of tobacco, dietary factors, obesity, and lack of exercise.¹⁵

The most effective means of preventing cancer is to reduce the use of tobacco products since an estimated 30% of all cancer deaths can be attributed to tobacco use. Scientific studies have shown that involuntary exposure of non-smokers to smoke from tobacco products (i.e. environmental tobacco smoke) poses a health risk for non-smokers, including an increased risk of lung cancer. Tobacco is causally related to cancers of the lung and bronchus, mouth, larynx, esophagus, bladder, kidney, and pancreas and may be related to cancers of the colon and cervix.¹⁶

An estimated 30%–35% of all cancer deaths can be attributed to nutrition and its effect on obesity and lack of physical activity.¹⁷ Evidence indicates that a diet that reduces cancer risk should be high in vegetables and fruits, and low in red meat and salt.

An estimated 4%–5% of all cancer deaths can be attributed to occupational exposure to carcinogens. Some chemicals (e.g., benzene, asbestos, vinyl chloride, arsenic, aflatoxin) show evidence of causing cancer in humans. Other chemicals are considered “probable” human carcinogens based on evidence from animal experiments (e.g., chloroform, DDT, formaldehyde, PCBs).¹⁸

Approximately 5% of cancer deaths are attributed to heredity. That is, certain individuals are more susceptible to developing cancer due to family history and/or because they have inherited genetic changes.¹⁹

Viruses and other infectious agents are estimated to cause 5% of cancer deaths. For example, the human papilloma virus (HPV) types 16 and 18 cause cervical cancer and are associated with oral cancer, and the hepatitis B virus may cause cancer of the liver.²⁰

Reproductive factors such as early age of menarche, late age at first birth, and late age at menopause may increase the risk for breast cancer. Women who have not had children are at greater risk for developing cancers of the endometrium and ovary.²¹

Alcohol use interacts with tobacco in the causation of oral cancer and cancers of the upper respiratory system and gastrointestinal tract.²² The combination of alcohol and tobacco use increases the risk significantly more than the use of tobacco or alcohol alone in the upper respiratory system and gastrointestinal tract.

Exposure to ultraviolet radiation from the sun is responsible for over 90% of skin cancers, including

Table 1.7
Estimated Annual Costs of Cancer Care in the United States and Maryland, 2002

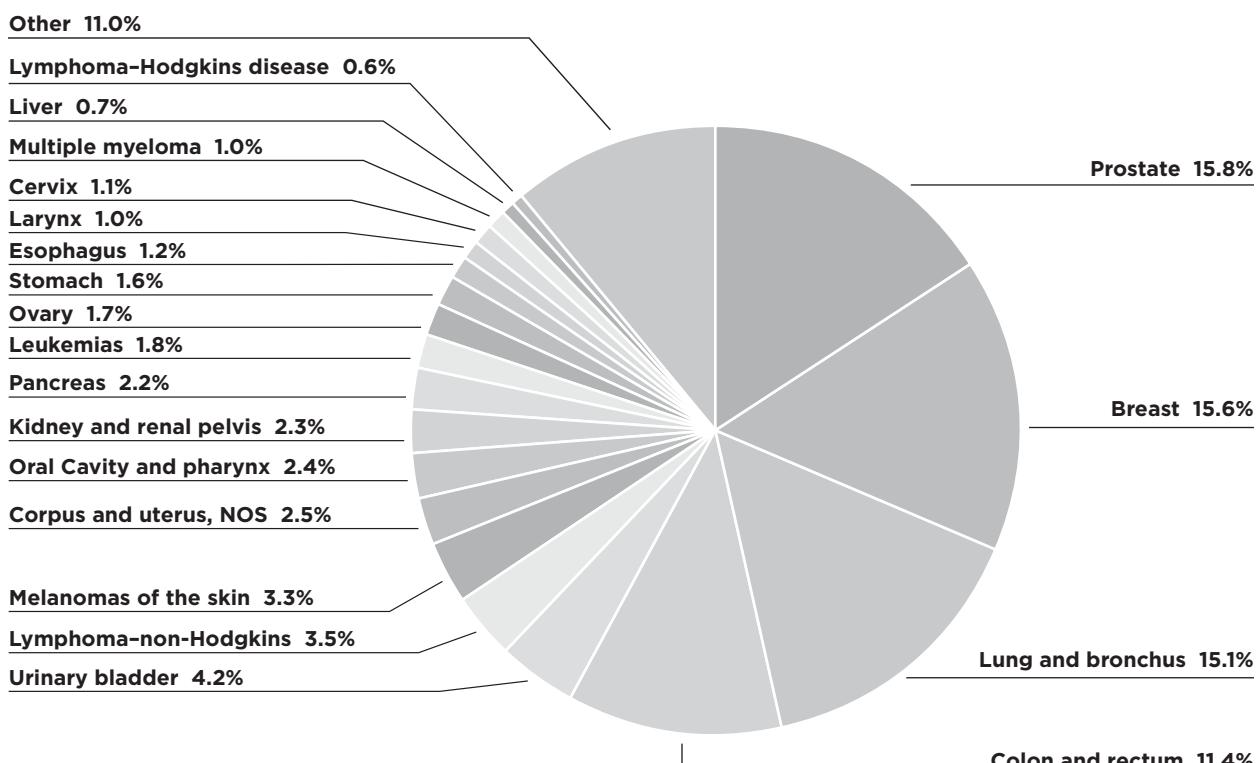
Cancer Type	Estimated Annual Costs in the U.S.	Estimated Annual Costs in MD
Total cancer care	\$171.6 billion	\$3.2 billion
Total direct medical costs	\$60.9 billion	\$1.1 billion
Direct Medical Costs by Cancer Type		
Breast cancer	\$5.45 billion	\$102.5 million
Colorectal cancer	\$5.45 billion	\$102.5 million
Lung and bronchus	\$5.00 billion	\$94.0 million
Prostate cancer	\$4.68 billion	\$88.0 million
Cervical cancer	\$1.68 billion	\$31.6 million
Head and neck cancers	\$1.61 billion	\$30.3 million
Melanoma	\$.70 billion	\$13.2 million

Source: American Cancer Society, Facts and Figures, 2003 (for U.S. data for total cancer care and total direct medical costs); SEER-Medicare database, personal communication, Martin L. Brown, Ph.D., Applied Research Program, National Cancer Institute (for U.S. data on direct medical costs by cancer type); Maryland DHMH, Center for Cancer Surveillance and Control (estimated annual costs in Maryland are based on the assumption that Maryland represents 1.88% of the U.S. population).

Table 1.8
Estimated Proportion of Cancer Deaths Attributable to Various Risk Factors

Risk Factor	Doll and Peto Estimate	Harvard Estimate
Tobacco	30%	30%
Adult diet/obesity	35%	30%
Sedentary lifestyle	-	5%
Occupational factors	4%	5%
Family history of cancer	-	5%
Viruses/other biologic agents	10%	5%
Perinatal factors/growth	-	5%
Reproductive factors	7%	3%
Alcohol	3%	3%
Socioeconomic status	-	3%
Environmental pollution	2%	2%
Ionizing/ultraviolet radiation	3%	2%
Prescription drugs/medical procedures	1%	1%
Salt/other food additives/contaminants	-	1%

Source: Doll R, Peto R. The Causes of Cancer. Quantitative Estimates of Avoidable Risks of Cancer in the United States Today. New York, NY: Oxford University Press, Inc.; 1981 and the Harvard Center for Cancer Prevention. Harvard Report on Cancer Prevention. Volume 1: Causes of human cancer. <http://www.hsph.harvard.edu/cancer/publications/reports.html>.

Figure 1.11**Percent of All Incident Cancer Cases by Type of Cancer in Maryland, 1995-1999***

*Total incident cases reported 1995-1999 = 120,182.

Source: Maryland Cancer Registry, 1995-1999.

melanoma. Prolonged sun exposure, a history of severe sunburns, and sunburns during childhood have been implicated in the development of skin cancer. Radon exposure in homes can increase lung cancer risk, and cigarette smoking greatly increases the effect of radon exposure on lung cancer risk.²³

Risk factors vary for different cancer sites (Table 1.9).

Disparities

Blacks are more likely to die from cancer than persons from any other racial or ethnic group in Maryland. In 1999, the overall cancer mortality rate for blacks in Maryland was 257.9 deaths per 100,000 population compared to a rate of 204.0 deaths per 100,000 population for whites in the state (Table 1.2). These data show that the cancer mortality rate for Maryland blacks is 26% higher than the cancer mortality rate for Maryland whites.²⁴ Black males have the highest overall cancer incidence and mortality rates compared to black females, white males, and white females (Figure 1.3).

Despite these high rates among blacks, cancer incidence and mortality decreased more among blacks than whites in Maryland from 1995 to 1999. Between 1995 and 1999, overall cancer incidence rates declined an average of 3.4% for all races, 6.2% for blacks, and 2.8% for whites in Maryland. Similarly, the death rate for all cancers in Maryland decreased an average of 1.9% per year for all races, 3.0% for blacks, and 1.5% for whites.²⁵ These data show that gains are being made to lessen the disparities in cancer incidence and mortality in Maryland, but much more work remains to be done.

Cancer Control Model for Maryland

A Cancer Control Model has been developed in Maryland to provide a framework for decisionmaking regarding cancer control policies and services in the state. (Figure 1.12.) The underlying principle of the Cancer Control Model is the importance of using scientific evidence to guide the development and imple-

Table 1.9
Select Cancer Types and Associated Risk Factors

Cancer Type	Risk Factors
Breast cancer	Age; personal and family history of breast cancer; atypical hyperplasia; early menarche; late menopause; obesity after menopause; recent use of oral contraceptives or postmenopausal estrogens and progestins; never giving birth to children or giving birth after age 30; alcohol; inherited genes.
Colon and rectum	Age; personal and family history of colorectal cancer or polyps; inflammatory bowel disease; smoking; alcohol consumption; obesity; physical inactivity; high fat and low fiber diet; inadequate intake of vegetables and fruits.
Leukemia	The causes of most leukemia are unknown. Some risk factors are genetic abnormalities (Down's syndrome); cigarette smoking; benzene; ionizing radiation; human T-cell leukemia/lymphoma retrovirus (HTLV-1).
Lung and bronchus	Cigarette smoking is by far the most important risk factor in the development of lung cancer. Other risk factors: occupational or environmental exposure to arsenic and some organic chemicals like radon and asbestos (particularly among smokers); radiation exposure from occupational, medical, and environmental sources; air pollution; tuberculosis; and for non-smokers, environmental tobacco smoke.
Lymphoma	Risk factors are largely unknown, but may involve reduced immune function (e.g., organ transplants) and exposure to infectious agents (HIV, HTLV-1); age; occupational exposure to herbicides.
Oral cavity and pharynx	Cigarette, cigar, or pipe smoking; use of smokeless tobacco; excessive consumption of alcohol.
Ovary	Age; never giving birth; use of fertility drugs; hormone replacement therapy; personal history of breast cancer; family history of breast or ovarian cancer; hereditary nonpolyposis colon cancer.
Pancreas	Cigarette and cigar smoking; obesity; physical inactivity; chronic pancreatitis; diabetes; cirrhosis; a diet high in fat.
Prostate	Age; black race; and family history of prostate cancer.

Table 1.9
Select Cancer Types and Associated Risk Factors

Cancer Type	Risk Factors
Skin	Excessive exposure to ultraviolet radiation from sunlight or tanning lamps; fair complexion; occupational exposure to coal tar, pitch, creosote, arsenic compounds, or radium; family history; and multiple or atypical moles.
Urinary bladder	Smoking is the greatest risk factor for bladder cancer. Other risk factors include: living in an urban area; workers in dye, rubber, or leather industries.
Uterine cervix	Human papilloma virus (HPV); having sex at an early age; many sexual partners; cigarette smoking.
Uterine corpus (endometrium)	High cumulative exposure to estrogen is the major risk factor for endometrial cancer, the most common type of cancer of the uterine corpus (e.g., estrogen from estrogen replacement therapy, tamoxifen, early menstruation, late menopause, never giving birth, a history of failure to ovulate, and obesity). Other risk factors for uterine corpus cancer include infertility and hereditary nonpolyposis colorectal cancer.

Source: American Cancer Society, Facts and Figures, 2003.

mentation of cancer control policies and services in the state. Focusing policies and services on those that are evidence-based maximizes the use of limited resources in the most effective way to reduce the burden of cancer among the citizens of Maryland.

Cancer control starts with research. Basic research involves discovering new knowledge about the causes and etiology of cancer as well as new ways to detect, diagnose, and treat cancer effectively. Basic research is translated into interventions and technologies that can then be applied to individual patients, communities, and the general population. Research demonstrates which interventions are most effective in reducing incidence, morbidity, and mortality. For example, the results of clinical trials provide information on the best methods to detect, diagnose, and treat individuals with different types of cancer. Cancer research is of the utmost importance in furthering our knowledge in cancer control.

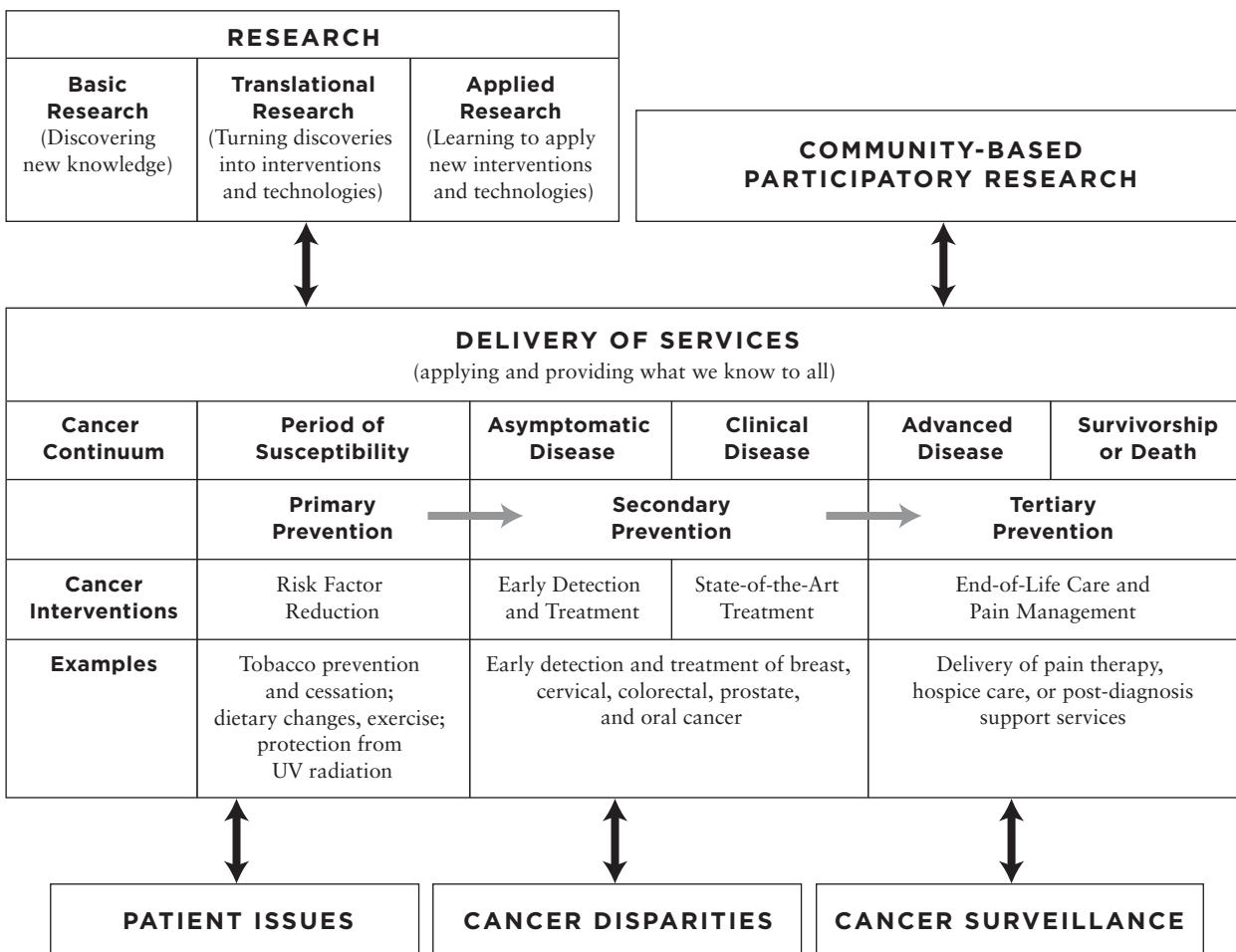
Community-based participatory research is a collabora-

tive approach to research in which communities are actively engaged in the research process through partnerships with academic institutions. Community-based participatory research recognizes the unique strengths that each partner brings. It begins with a research topic of importance to the community and aims to combine knowledge with action to achieve social change, improve health outcomes, and eliminate health disparities.²⁶

In recent years, national organizations, funding agencies, and researchers have called for a renewed focus on community-based participatory research, recognizing the importance of social, political, and economic systems to health behaviors and outcomes. This renewed focus is due to many converging factors, including our increased understanding of the complex issues that affect health, the importance of both qualitative and quantitative research methods, and the need to translate the findings of basic, interventional, and applied research into changes in practice and policy.²⁷

For an individual, the Cancer Control Model follows a

Figure 1.12
Cancer Control Model for Maryland



Source: Adapted from: 1999 Annual Cancer Report for the President's Panel and unpublished writings of John W. Southard, M.D., M.P.H., formerly with the Office of Chronic Disease Prevention, MD DHMH.

continuum from a period of susceptibility to asymptomatic disease, clinical disease, advanced disease, and survivorship or death. During the period of susceptibility, a person is healthy and has not developed cancer. During this period, primary prevention or risk reduction activities should be undertaken. Primary prevention refers to approaches to prevent or reduce the occurrence of disease (e.g., cancer) among individuals who are susceptible to developing the disease. Examples of evidence-based primary prevention interventions in cancer control are tobacco prevention and cessation, dietary changes and increased physical activity, and reduction of sun exposure.

During the period of asymptomatic disease, a person has developed cancer but has not developed any signs or symptoms of the disease. During the period of clin-

ical disease, a person has developed cancer and has signs or symptoms of the disease. During these periods, early detection and state-of-the-art treatment (secondary prevention) are vital. Clinical trials have demonstrated that the early detection and treatment of breast cancer and colorectal cancer can significantly reduce mortality due to these cancers. The early detection of cervical cancer has resulted in a reduction in both the incidence of, and mortality from, this disease. Research has improved treatment of many types of cancer, resulting in improved survival and reduced mortality. Clinical trials are ongoing to learn better ways to detect, diagnose, and treat different types of cancers.

During the period of advanced disease, efforts are needed to improve quality of life and survival as well as reduce morbidity, disability, and death. This can be

accomplished through state-of-the-art treatment, end-of-life-care, and pain management. These approaches are termed tertiary prevention.

Throughout the cancer continuum, there are issues that warrant special consideration. Patients, their families, and their significant others are affected in a myriad of ways throughout the entire cancer control process and have special needs warranting attention. In addition, cancer disparities exist at each step in the cancer continuum and they too must be addressed.

Lastly, cancer surveillance is needed to collect, analyze, and report data and information to inform policy makers about interventions that are working and those that are not.

At the state level, the first step in the Cancer Control Model is to identify those interventions that have been proven, through research, to reduce death, disability, and incidence, and/or improve survival of cancer along the cancer continuum (Appendix B, Table 1). The next step is to determine if these proven interventions are being used by all racial and ethnic groups and in all geographic areas of the state. Gaps in the provision of these proven interventions should be identified, and evidence-based public health policies and services should be implemented to assure the provision of these proven interventions among communities that are not being reached, filling gaps in services, education, and access to care (Appendix B). In this way, the Cancer Control Model can help guide interventions and policies in the state to help reduce the burden of cancer among Maryland's citizens.

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CHAPTER 2

CANCER SURVEILLANCE

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CANCER SURVEILLANCE

A key to improving cancer control in Maryland is cancer surveillance. Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice. It involves the tracking of data and is closely integrated with the timely dissemination of these data to those who need it.¹ Additionally, surveillance can provide data to raise awareness of public health problems and support the development of policies.

Cancer surveillance utilizes data such as the occurrence of cancer (incidence), cancer deaths (mortality), risk factors for the development of cancer (e.g., smoking, overweight, fruit and vegetable intake), cancer screening behaviors (e.g., the use of mammography, colonoscopy, Pap tests), and diagnostic and treatment services in the population. In a well-functioning cancer surveillance system complete, timely, and high quality data are transformed into information that is easily accessible to those who use it to prevent and control cancer. Figure 2.1 illustrates the key elements of cancer surveillance.²

Cancer data and information have many uses including planning, policy-making activities such as resource allocation, evaluation of cancer prevention and control efforts, and applied research into the reasons behind the numbers.

This chapter utilizes case studies to illustrate real examples and situations where cancer surveillance information has contributed to public health action: the monitoring and evaluation of programs, policy making (including resource allocation), and applied research.

For example, data from the Maryland Department of Health & Mental Hygiene (DHMH), the Maryland Cancer Registry, and Maryland Vital Statistics have provided information that allows better understanding of the scope of the breast cancer problem in Maryland and expanded breast cancer screening services (Table 2.1).

In the past, cancer surveillance data were used in the development of the *Report of the Governor's Task Force to Conquer Cancer in Maryland* and the *Report of the Task Force to End Smoking in Maryland*.^{4,5} These reports provided policy direction for the allocation of funds and priorities under the tobacco settlement for the Cigarette Restitution Fund Program (CRF) in Maryland (Table 2.2).

Tracking cancer incidence and mortality rates over time to determine emerging trends is another aspect of cancer surveillance. One example of an important use of cancer surveillance data is to combine what is known about trends in cancer incidence (from the Maryland Cancer Registry) and mortality (from Vital Statistics) with trends in the aging of the population to

Table 2.1

**Cancer Surveillance Case Study:
Cancer Surveillance Leads to
Breast Cancer Screening Programs
(Planning)**

Cancer Surveillance Information:

- Maryland was among the top ten states in the nation with high breast cancer mortality rates in 1991. (Source: Maryland Vital Statistics, NCHS)
- Breast cancer incidence rates in Maryland were higher than those in the nation.
(Source: Maryland Cancer Registry, SEER)
- Research indicated that breast cancer mortality could be reduced by approximately 30% with early detection and treatment.

State, Local, or Community Action:

The Health Services Cost Review Commission's (HSCRC) Illness Prevention Program was expanded in 1989 to include breast cancer screening proposals from Maryland hospitals. The Maryland Department of Health & Mental Hygiene provided technical assistance to hospitals applying for these dollars.

Results:

By 1992, 28 Maryland hospitals had applied for and received grant funding from the HSCRC to conduct local breast cancer screening programs for underserved women. Between 1989 and 1995, 34,000 women were screened, 45,000 mammograms were performed, and 366 women were diagnosed with breast cancer.

project the future burden of cancer in Maryland. This is an especially important issue because the baby boomer generation is entering the ages of greatest cancer incidence. Projecting the number of persons likely to be diagnosed with cancer in the future can help Maryland to plan for cancer prevention, education, and early detection programs as well as cancer diagnostic and treatment services (e.g., hospital beds, physician and nursing staffing, outpatient surgery and chemotherapy services, and rehabilitative, home health, and hospice care) and to foster cancer research.

Cancer surveillance data can be used to evaluate cancer prevention and control programs by monitoring trends in cancer incidence, stage, and mortality over time. For

Table 2.2

**Cancer Surveillance Case Study:
Cancer Surveillance and the
Maryland Tobacco Settlement
(Resource Allocation)**

Cancer Surveillance Information:

- Maryland ranked among the top states in cancer mortality in 1998. (Source: Maryland Division of Health Statistics, National Center for Health Statistics)
- More than \$3 billion is spent on the direct and indirect costs of smoking in Maryland per year.⁶
- Tobacco use is the leading cause of preventable deaths, including those due to cancer.⁷

State, Local, or Community Action:

In 1998, Maryland joined other states in a lawsuit against tobacco manufacturers to recover Medicaid costs associated with the treatment of smoking-related illness.

Results:

The state of Maryland is a signatory party to the master tobacco settlement agreement reached via multi-state litigation against the tobacco manufacturers. The Maryland Cigarette Restitution Fund Program was established in 2000 and is used to fund:

- tobacco-use prevention and cessation programs
- cancer prevention, education, screening, and treatment programs
- cancer research programs
- a tobacco crop conversion program.

example, cancer mortality rates in Maryland have been decreasing at a faster rate than that of the nation. For the time period 1986–1990, Maryland had the third highest cancer mortality rate in the nation; for the time period 1991–1995, Maryland ranked sixth highest; and for the time period 1996–2000, Maryland's rank dropped to the 11th highest cancer mortality rate in the nation.⁸

Cancer surveillance can support population-based research studies aimed at better understanding the cancer problem in Maryland. For example, data from the Maryland Cancer Registry was used for one research study to understand the geographic pattern of prostate cancer in the state (Table 2.3).

Table 2.3
Cancer Surveillance Case Study:
Prostate Cancer (Research)

Cancer Surveillance Information:

Prostate cancer is the most frequently reported cancer among Maryland men. Nationally, the mortality rate for prostate cancer is twice as high among black males than white males.

(Source: Maryland Cancer Registry, National Center for Health Statistics)

State, Local, or Community Action:

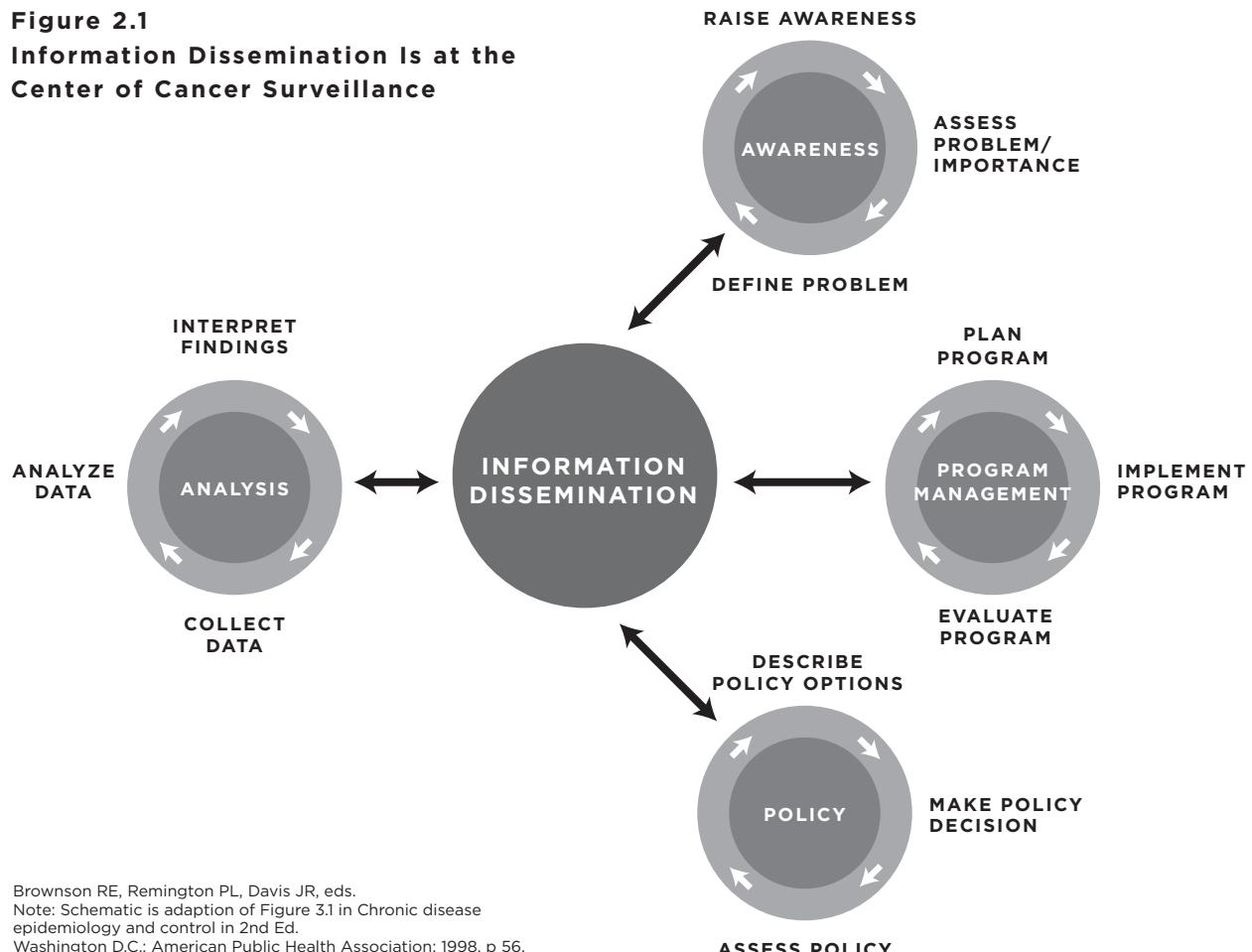
- The Johns Hopkins Bloomberg School of Public Health received a grant from the Centers for Disease Control and Prevention to investigate racial and geographic variations of prostate cancer incidence in Maryland.
- The Johns Hopkins investigators obtained and geo-coded prostate cancer data from the

Maryland Cancer Registry. Geo-coding data is a process that involves associating address information with a geographic location, which enables placement of a cancer case within a state, a county, and a zip code.

Results:

- While the analysis is still underway, preliminary results have highlighted areas of increased prostate cancer incidence.
- In addition, the analysis also identified a need to develop a mechanism for geo-coding post office box addresses. The investigators are collaborating with the Maryland Cancer Registry to obtain additional funding to develop methodology and software that central cancer registries can use to improve the effectiveness of geo-coding cancer registry data.

Figure 2.1
Information Dissemination Is at the Center of Cancer Surveillance



Databases Used for Cancer Surveillance in Maryland

In Maryland, cancer surveillance is supported by data from a variety of sources, including the Maryland Cancer Registry, the Maryland Vital Statistics Administration, the Maryland Behavioral Risk Factor Surveillance System, the Maryland Cancer Survey, and other databases, surveys, and research. Table 2.4 is a compilation of Maryland and federal databases that can be used for cancer and cancer-related surveillance. The table includes information on purpose, availability, and limitations of each database. These databases collectively represent the spectrum of cancer and cancer-related events occurring in Maryland. The Maryland Cancer Registry is a population-based database that collects information on all new cases of cancer in Maryland. The Maryland Vital Statistics Administration collects information from death certificates on all deaths in Maryland, including cancer deaths. The Maryland Hospital Discharge database, which is administered by the Health Services Cost Review Commission, collects medical information about individuals discharged from hospitals in Maryland. The Maryland Medical Care database, which is administered by the Maryland Health Care Commission, collects data on physicians' services provided to Maryland residents who have private health insurance. The Maryland Behavioral Risk Factor Surveillance System (BRFSS), which is administered by the DHMH, is a statewide telephone survey that collects information on knowledge and behavior of Maryland adults aged 18 and older related to major health conditions, such as screening for various types of cancer. The Maryland Cancer Survey (MCS), which is administered by the DHMH, is a statewide telephone survey that collects information on cancer risk factors and screening practices of Maryland adults aged 40 and older. The Maryland Adult Tobacco Survey (MATS) and Maryland Youth Tobacco Survey (MYTS) collect information on the use of tobacco products by Maryland adults and youth, respectively. The Maryland Oral Cancer Survey is a telephone survey that collects information on oral cancer risk factors and screening practices of Maryland adults aged 18 and older. The Maryland Statewide Health Network Baseline Survey of Maryland Counties (MSHN) is a telephone survey that collects information on cancer attitudes, knowledge, and practices of Maryland adults aged 18 and older in three regions of the state (Western Maryland, Baltimore City, and the Eastern Shore). The Maryland Medicaid Management Information System (MMIS) collects medical information on Maryland Medicaid recipients.

Some of these databases collect information for the entire population in Maryland (e.g. the Maryland Cancer Registry, the Maryland Vital Statistics Administration); other databases use a representative sample to collect information on Marylanders (e.g., BRFSS, MCS, MATS, MYTS). The remaining databases have information on certain segments of the Maryland population (e.g., the Maryland Medical Care database, MSHN, MMIS) such as the population served through Medicaid.

In addition, there are several federal databases that are used in cancer surveillance (also listed in Table 2.4). The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results Program (SEER) collects information on cancer incidence, stage, and survival from 11 cancer registries throughout the United States that are estimated to represent 14% of the U.S. population. (The NCI State Cancer Profiles is a tool for visualizing data through tables and graphs for the nation or by state.) The Centers for Disease Control and Prevention (CDC) National Program of Cancer Registries (NPCR) collects information from all states that have state cancer registries. The NPCR published its first report of cancer incidence in the nation, in coordination with SEER, in 2002. The National Center for Health Statistics has several databases. The NCHS National Vital Statistics System collects information on cancer mortality from each of the states in the nation. The NCHS National Health Interview Survey (NHIS) is a continuous in-person interview survey conducted on a random sample of households in the country that collects information on illness and disability (including cancer) in the nation. The NCHS's National Health and Nutrition Examination Survey (NHANES) collects information on the health and nutritional status of adults and children in the United States. The Environmental Protection Agency has numerous databases that can be consulted for cancer-related information. The U.S. databases are useful for comparison when statewide data is available and can inform users of national trends when state-specific information is not available.

Surveillance systems are designed to answer basic questions, generally about the entire population. Questions having more detail, greater depth, or broader scope require special research studies and are frequently initiated by scientists. Table 2.5 lists examples of questions that can be answered by the various databases used for cancer surveillance.

Table 2.4**Maryland Cancer-Related Database Summary: Databases That Can Be Used for Cancer Surveillance**

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Cancer Registry DHMH, Family Health Administration, Center for Cancer Surveillance and Control 410-767-5521 www.fha.state.md.us	To register cancer incidence among Maryland residents	All Maryland residents; age, race/ethnicity, date of diagnosis, county of residence	1992–2001	Aggregate data available; release of county or case-based data requires approval by the DHMH Institutional Review Board	Cancer site, stage; patient's age at diagnosis, race, sex, county of residence	NAACCR contributors, other states, Canada, Mexico, SEER on basic cancer measures	No information on survival status; limited detail on stage of cancer, occupation, and other risk factors (smoking, screening)
MD Behavioral Risk Factor Surveillance System (BRFSS) DHMH, Family Health Administration, Center for Prevention Health Services 410-767-5159 www.marylandbrfss.org ; www.cdc.gov/brfss	To collect population-based behavioral health data about chronic diseases, injuries, and preventive health services that contribute to premature morbidity or mortality	4,400 telephone surveys from MD, English-speaking adults aged 18 and over; stratified sample based on urban or rural telephone prefix/exchange; age, race, ethnicity, sex, marital status, education, employment, income, county of residence	1988–2001	User-generated reports available on MD DHMH website for estimates where the sample is >50 surveys; user-generated reports available on CDC website, statewide only; CD-ROM data available for 1990–2001 from CDC	MD residents aged 40 and over who have had a colonoscopy within the past 2 years; mammography, exercise, nutrition, and overweight	National and other state BRFSS studies, Maryland Cancer Survey, Oral Cancer Survey, and Maryland Statewide Health Network Survey	Annual data not available for some counties; no data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non-coverage due to households without phones; estimates based on sample sizes <50 should be interpreted with caution
MD Cancer Survey (MCS) DHMH, Family Health Administration, Center for Cancer Surveillance and Control 410-767-0791 Website: www.fha.state.md.us/cancer/pdf/MCS_Report_2002-V3.pdf	To collect population-based behavioral and health data related to cancer surveillance and screening practices	5,000 telephone surveys from MD, English-speaking adults aged 40 and over; stratified sample based on urban or rural telephone prefix/exchanges; same demographics as BRFSS	2002	Report available at website; data use policy being developed	MD residents aged 40 and over who have undergone cancer screening; similar to BRFSS	National and state BRFSS, Oral Cancer Survey, and MD Statewide Health Network Survey	Persons <40 years old not captured; no data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non-coverage due to households without phones; estimates based on sample sizes <50 should be interpreted with caution

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Vital Statistics Administration 410-767-5950 www.mdpublichealth.org/vsa	To administer birth/death certification and summarize mortality statistics for administrative and public health use	All births/deaths among Maryland residents; year of death, place, date and age at death, place of birth, race, ethnicity, sex, cause(s) of death	Data files: 1970 to present; vital statistics reports: 1960 to present	Aggregate and county level data available upon request; release of single-record data requires DHMH Institutional Review Board approval; public-use data available through CDC	Age, race, Hispanic origin, sex, marital status, education, occupation, residence, place of death, cause of death, manner of death	National Vital Statistics System (NVSS) collected by the National Center for Health Statistics (NCHS); standards set by NCHS	Verification of cause of death information is not possible; lack of automated death registration delays public health analysis
MD Adult Tobacco Survey (MATS) and MD Youth Tobacco Survey (MYTS) DHMH, Family Health Administration/Office of Health Promotion, Education and Tobacco-Use Prevention 410-767-1362 www.fha.state.md.us/crfp/html/stats.cfm	To collect behavioral, lifestyle, and other data supporting CRF's Tobacco-Use Prevention and Cessation Program	MATS: 16,596 telephone surveys from MD, English-speaking adults aged 18 and over; sample stratified by jurisdiction MYTS: 55,967 middle and high school-based surveys; 2-stage cluster sample generated for each jurisdiction	MATS: 2000 MYTS: 2000 and 2002	September 1st of each year for prior year; Data Use Policy is in development; county level data are available	Prevalence of tobacco use (all tobacco products); tobacco cessation; attitudes, knowledge about tobacco use, social context, and exposure to second-hand smoke	MATS: BRFSS MYTS: National Youth Tobacco Survey (NYTS) and youth tobacco surveys in other states	Some minority populations may be under-represented; MATS: No data on non-English speaking residents; self-reported data and refusals to answer the survey or parts of it; non-coverage due to households without phones MYTS: Excludes school dropouts, students whose parents refused to let them participate, and those who were absent during survey
MD Hospital Discharge Database DHMH, MD Health Care Commission, HSCRC 410-764-2605 www.hscrc.state.md.us	To provide a standard set of data about each hospital discharge or ambulatory care visit; hospital rate setting	Patients served by Maryland's 66 general hospitals, not including specialty hospitals (e.g., chronic care)	Data files: 1980 to present Electronic files: 1996 to present	Confidential and unidentified formats available; hospital and patient's jurisdiction are captured; out-of-state patients are normally excluded from analysis	Discharges include ICD-9* codes for primary, secondary diagnosis and CPT** codes of procedures or procedures due to cancers listed as the primary diagnosis, by jurisdiction of residence or hospital	National Hospital Discharge Survey (NHDS) collected by the National Center for Health Statistics (NCHS) and other states' hospital discharge databases	Does not assure that cancer is captured if cancer is not listed as one of discharged diagnoses

Table 2.4
Maryland Cancer-Related Database Summary:
Databases That Can Be Used for Cancer Surveillance

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Medical Care Database DHMH, MD Health Care Commission, Data Systems & Analysis 410-764-3570 www.mhcc.state.md.us/ database/_database.htm	To support policy decision making; health options, health market, and cost and utilization patterns	Practitioner fee-for- service encounters and prescription drug cov- erage among MD resi- dents privately insured or insured through HMOs	1996–2001	Detailed data avail- able down to zip code and county level; patient ID is encrypt- ed; data available 1 year after collected	Coverage type, claim-related conditions, diagnosis code, procedure code, reimbursement amount	Medical care items are often compared with SEER data; this system does not encompass entire Maryland population	Excludes services provided for self-pay, Medicaid, and unin- sured populations; excludes MD residents who work out of state, are self-insured, or insured through self- funded employers; does not include insti- tutional bills; data for HMOs excludes pri- mary encounters; rates not available due to lack of population denominators
MD Oral Cancer Survey DHMH, Family Health Administration, Office of Oral Health 410-767-5736	To collect knowledge and behavioral data relating to oral cancer risk factors, signs, symptoms, and dental health screening exams	1,127 telephone surveys from MD, English-speaking adults aged 18 and over; over sampling of African-American men; age, race, ethnicity, sex, status, education	First survey: September 2002	Data available approximately 6 months from end of collection; data-use policy is pending; county-level data is not available	MD residents aged 18 and over who have undergone oral cancer exams in the past year	Some comparability to BRFSS and MCS	No data on non- English speaking resi- dents; self-reported data and refusals to answer the survey or parts of it; non-cover- age due to households without phones; estimates based on samples <50 should be interpreted with caution; county- and region-specific data not available

Database/System Contact Phone No. Website for Reports and/or Data	Main Purpose	Demographic and Geographic Coverage	Years of Available Data	Data Availability	Examples of Data Collected	Comparability with U.S. and Other State Reports on Cancer Outcomes	Notes/ Limitations
MD Statewide Health Network (MSHN) Baseline Survey University of Maryland, School of Medicine, Office of Policy and Planning 410-706-1742	To examine health attitudes, knowledge, and practices of MD residents in three regions (Baltimore City, Western MD, and the Eastern Shore)	Approximately 500 interviews per county among English-speaking MD adults aged 18 and over; general demographic information	First survey; ongoing as of July 2003	Data-use policy in development; internal data use with strict discretion; lag time from collection to dissemination TBD	Knowledge, attitudes, and practices relating to health behaviors; insurance, preventive services for lung, skin, breast, colon, prostate, cervical, and oral cancers; other tobacco-related diseases, CVD, (hypertension, stroke)	Some comparability to BRFSS and the Commonwealth Fund	Only includes data from selected jurisdictions in the state
Maryland Medicaid Management Information Systems II DHMH, Medical Care Programs, Medicaid Operations, Data Management & Analysis, Office of Planning & Finance 410-767-5683	To collect medical, administrative, and billing information to monitor financial transactions for Medicaid recipients	Maryland Medicaid recipients	1995–2002 (earlier years available)	Aggregate data available on request; release of identifiable data requires DHMH Institutional Review Board approval; county level data is available	Demographics, disease prevalence (ICD-9*); treatment (e.g., inpatient, outpatient, hospital, physician) by procedure code	Compares with national and state Medicaid administrative databases	Does not specify whether the diagnoses listed are suspected and being ruled out or are confirmed

*ICD-9 refers to the American Medical Association's *International Classification of Diseases*.

**CPT refers to the American Medical Association's *Current Procedural Terminology*.

National Cancer-Related Surveillance Systems

Database/System	Website	Focus
National Cancer Institute		Incidence, mortality, cancer prevalence, and reports
■ Surveillance, Epidemiology, and End Results (SEER)	www.seer.cancer.gov/publications	
■ Wonder	http://wonder.cdc.gov	
■ State Cancer Profiles	www.statecancerprofiles.cancer.gov	
Centers for Disease Control and Prevention		Incidence; incidence and mortality
■ National Program of Cancer Registries	www.cdc.gov/cancer/npcr	
■ State/Territory Cancer Data	www.cdc.gov/cancer/dbdata.htm	
National Center for Health Statistics (NCHS)		
■ National Health Interview Survey (NHIS)	www.cdc.gov/nchs/nhis.htm	41,000 household interviews annually on health behaviors, chronic conditions, health care coverage and use, and health status and limitations; periodic modules include: cancer, HP2010, diabetes
■ National Health and Nutrition Examination Survey (NHANES)	www.cdc.gov/nchs/nhanes.htm	Health and nutritional status of adults and children in the U.S.; examples of data include: disease or condition prevalence, risk factors, nutrition monitoring, growth and development, disease monitoring
■ National Vital Statistics System (NVSS)	www.cdc.gov/nchs/nvss.htm	Death rates
■ CDC WONDER	http://wonder.cdc.gov	Death rates
Other		Incidence and mortality, cancer facts and figures, reports from 1997-2002 by state; various environmental databases
■ American Cancer Society (ACS)	www.cancer.org/docroot/home/index.asp	
■ Environmental Protection Agency	www.epa.gov (search for databases)	

Table 2.5
Examples of Questions that Surveillance Systems Can Answer in Maryland

Sample Questions About Cancer in Maryland	Cancer Surveillance Source	Answer
How many men had lung cancer in Maryland in 1999?	Maryland Cancer Registry	In 1999, 1,904 cases of lung cancer were reported among men in Maryland.
How many women died of breast cancer in Cecil County in 2000?	Maryland DHMH Vital Statistics	In 1999, 10 breast cancer deaths were reported among women in Cecil County, Maryland.
How does Maryland's rate of colorectal cancer compare with the United States?	Maryland Cancer Registry; SEER (U.S.)	Compared to the U.S. (53.3 per 100,000 population), the Maryland 1999 incidence rate is not statistically significantly different (54.3 per 100,000 population).
Does the Eastern Shore have a higher rate of breast cancer mortality than Western Maryland?	Maryland Cancer Registry	The Eastern Shore has 30.9 breast cancer deaths per 100,000 population compared to 27.2 breast cancer deaths per 100,000 population in Western Maryland (1995–1999 data). The rate is not statistically significantly different.
Do black men have a higher rate of prostate cancer than white men of the same age in Baltimore City?	Maryland Cancer Registry	In 1999, black men in Baltimore City had a higher prostate cancer incidence rate (236.7 per 100,000 population) than white men (168.8 per 100,000 population). This rate is statistically significantly higher.
What percent of melanoma cases in Maryland were diagnosed at an early stage in 1999?	Maryland Cancer Registry	In 1999, 43.6% of melanoma cases were diagnosed at an early stage in Maryland.
What percentage of Maryland adults and youth smoke or use tobacco products?	Maryland Adult Tobacco Survey Maryland Youth Tobacco Survey	In 2002, 19.8% of Maryland adults reported being current smokers. In 2002, 18.4% of youth in grades 9–12 reported being current smokers.
What percentage of Marylanders eat 5 or more vegetables and fruits each day?	Behavioral Risk Factor Surveillance System (BRFSS)	In 2000, 27.4% of Marylanders reported eating 5 or more fruits and vegetables a day.

Improvements in Cancer Surveillance in Maryland

Since publication of the 1996 Maryland Cancer Control Plan, there have been notable improvements in several of the cancer surveillance databases in Maryland. In addition, several new databases have been implemented since the 1996 cancer plan. The following improvements have expanded Maryland's ability to measure, track, and report changes in cancer control:

- The Maryland Cancer Registry has received the gold standard from the National Program of Cancer Registries for the quality and completeness of its data in 2001, 2002, and 2003. This means that complete, timely, and accurate data have been assembled to represent Maryland's cancer incidence. The Maryland Cancer Registry utilizes data from the Maryland Vital Statistics Administration to produce an annual report on cancer mortality in Maryland.
- The Maryland Vital Statistics Administration is using a computerized algorithm that is applied to determine the underlying cause of death when multiple causes of death are specified on Maryland death certificates. The Maryland Vital Statistics Administration Annual Report has become timelier and all reports since 1996 are available on the Internet.⁹
- The Maryland Behavioral Risk Factor Surveillance System (BRFSS) has increased its sample size from 3,600 interviews in 1996 to 4,800 interviews in 2002. The BRFSS regularly over-samples the rural areas of the state, enabling annual regional measurement of most risk factors and preventive services.¹⁰
- New surveys have been implemented, such as the Maryland Youth Tobacco Survey (2000 and 2002) and the Maryland Adult Tobacco Survey (2000),¹¹ the Maryland Medical Care database (1996-present), the Maryland Oral Cancer Survey (2002), and the Maryland Cancer Survey (2002), which give a clearer picture of cancer risk factors and screening in Maryland.
- Maryland's "Annual Cancer Report" has been published since the baseline report in 2000 under the Cigarette Restitution Fund Program, detail-

ing cancer outcomes in the state's priority areas.¹²

- The Maryland Cancer Registry Advisory Committee meets several times a year to advise the Maryland Cancer Registry on issues related to data quality, data use, and data dissemination.

Despite these important advances, there is more that can be done in cancer surveillance to accelerate analysis and promote cancer awareness, policy development, and program planning for cancer prevention and control in Maryland. Cancer surveillance in Maryland must move from "data rich" to "data smart."

Gaps in Cancer Surveillance in Maryland

The Cancer Surveillance Committee identified the following gaps in cancer surveillance. These gaps are listed in relationship to the steps in the cancer surveillance model depicted in Figure 2.1.

Gaps in Data Collection

- **Lack of all the data elements needed for cancer surveillance.** For example, stage of disease for various cancer sites reported to the Maryland Cancer Registry is incomplete. Survival status of all individuals diagnosed with cancer in Maryland is not available. (Survival rates refer to the proportion of individuals diagnosed with cancer who are alive at varying years after their diagnosis. Five-year relative survival rates are often used to monitor improvements in cancer treatment.) Other data elements are not completely reported to the Maryland Cancer Registry, such as occupational status, tobacco use, length of residency, etc. In addition, there may be a need for new analyses and qualitative studies, which may require additional data collection (e.g., quality of care data).
- **Lack of complete information on race, ethnicity, and place of residence for all new cases of cancer.** Ethnicity is under-reported to the Maryland Cancer Registry. The Maryland Cancer Registry is currently developing an algorithm to better estimate Hispanic ethnicity.
- **Need to improve the quality of data elements submitted to the Maryland Cancer Registry among selected facilities.** This could be accomplished by: increasing training of

tumor registrars; increasing the number of certified tumor registrars in Maryland who perform cancer registration; and increasing the number of American College of Surgeon-approved hospitals in Maryland.

- **Lack of quality control and quality assurance methods in some of the databases used for cancer surveillance.** For example, there is no quality assurance assessment of causes of death; this could lead to the possibility of misclassification errors. One study has suggested that a high proportion of prostate cancer deaths may have been due to other primary causes.

Gaps in Access to Cancer Data

- **Need for greater access to cancer surveillance information.** This could be accomplished in a number of ways, including the creation of public-use data files and interactive access (e.g., Web-based, user-defined utility reports) to databases used for cancer surveillance in Maryland. Public-use data files and user-defined utility reports allow easy access to data and allow analysis of data in aggregate groups (e.g., geographic area, race, sex, etc.), while protecting the confidentiality of the individuals represented in the dataset. Public-use data files and utility reports have been created for a number of federal databases such as the NPCR,¹³ BRFSS,¹⁴ and NCI SEER Program.¹⁵ The Centers for Disease Control and Prevention and the National Cancer Institute have recently collaborated to create a public-use cancer data file on state cancer profiles using state-based cancer incidence and mortality data.¹⁶ The Maryland Cancer Registry is currently collaborating with the NCI to develop a public-use data file for cancer incidence data in Maryland. Similarly, the Maryland BRFSS has developed a public-use data file. Public-use data files widen accessibility to data, shorten the time frame for analysis, and increase the likelihood that the data will be used.

Gaps in Data Analysis

The ability to proactively or reactively analyze cancer surveillance data must be expanded. This expansion may be accomplished in the following ways by:

- Training in statistics, including small area analysis, an analytic method used to determine the number of health (or other) events which occur

in small geographic areas such as zip codes, block groups, or census tracks (the goal of the analysis is to compare health events occurring in one area to those occurring in a similar geographic area or a larger, standard population)^{17,18}; training in cancer epidemiology and biology, including cancer in children; training in risk and health communication; and adaptation of the CDC's *Guidelines for Investigating Clusters and Health Events*. In order to analyze changes in cancer incidence within communities (smaller than a jurisdiction), for less common cancers, and within racial and ethnic groups, there is a need for expertise in, and new approaches to, small area analysis.

- Using analytic tools for small area analysis, geographic area analysis, and geographic information systems.
- Developing a list of leading cancer indicators (e.g., incidence, mortality, treatment, risk behaviors), avoidable cancer events, and events that are sentinels of problems in the delivery of cancer prevention, education, screening, and treatment services that can be used to monitor or track changes in cancer control in Maryland.
- It is vital to provide technical assistance to local health departments in cancer surveillance and analysis. Assistance from state agencies and academic health centers in analyzing local data, compiling county-specific data (including trends over time), and directing further studies or collection of additional data would have an impact on planning, targeting, and monitoring cancer programs.
- In addition, there is a need for expanded research into risk factors, etiology, and outcomes and the knowledge, attitudes, and behaviors of both the public and providers. The quality of care provided to cancer patients for selected cancers must be evaluated and CRF-funded research on surveillance-related topics must be encouraged. Of course, additional funding for research must be sought to accomplish these goals.

Gaps in Information Dissemination

- **Sub-optimal dissemination of existing cancer surveillance data to those who are implementing programs and policies**

to improve cancer control. These professionals, along with the general public, need increased access to cancer reports and cancer statistics in order to optimize the efforts of cancer surveillance. The Internet has proven to be effective in reaching those who wish to know.

In addition, each of the other chapters in this plan describes site-specific cancer surveillance needs and recommendations. This chapter's recommendations address overall cancer surveillance needs.



Cancer Surveillance Goals, Objectives, and Strategies

Goal:

Fully implement cancer surveillance—the development, collection, analysis, and dissemination of cancer information—in Maryland.

Target for Change

By 2008, increase the capacity to conduct cancer surveillance in Maryland.

Objective 1:

Develop, maintain, and enhance data systems to ensure accurate, timely, and complete information needed for the prevention and control of cancer.

Strategies:

1. Continue to support the Maryland Cancer Registry Advisory Committee in its role as advisor to the Maryland Cancer Registry on issues related to data quality, data use, and data dissemination.
2. Encourage the development of quality assurance and quality control methods in all databases used for cancer surveillance in Maryland.
3. Re-establish a statewide Cancer Surveillance Advisory Group to meet regularly to further cancer surveillance in Maryland.
4. Develop a set of leading cancer indicators (e.g., incidence, stage, survival, mortality, treatment, risk behaviors), avoidable cancer events, and events that are sentinels of problems in the delivery of cancer prevention and control services that can be used to monitor or track changes in cancer control in Maryland.
5. Facilitate standardized measurement of race, ethnicity, and geographic area in databases that can be used for cancer surveillance in Maryland.
6. Provide training opportunities for cancer registrars and other collectors of cancer-related data.
7. Increase the number of Certified Tumor Registrars in Maryland who actively work in cancer registration.
8. Explore barriers as to why hospitals do not have an in-house tumor registry.

**Objective 2:**

Expand access to, and analysis of, the databases used for cancer surveillance in Maryland in order to better meet the information needs of program planners, policy makers, researchers, and the public.

Strategies:

1. Continue to pursue the creation of a public-use (non-confidential) data file for databases that are used for cancer surveillance in Maryland.
2. Expand the interactive access (e.g., Web-based, user-defined utility reports) to databases used for cancer surveillance in Maryland.
3. Develop a list of priority research questions about specific Maryland cancer problems; share these research questions with potential funding sources, the statewide academic health centers, researchers, health leaders, and others.
4. Develop a guide/report that reviews, aggregates, and summarizes methodologies that local and state health agencies and others could use to address small numbers issues and assessment of disparities, while maximizing information and maintaining privacy.
5. Increase the capacity of state agencies to perform small area analysis of cancer-related events in Maryland.
6. Investigate the feasibility of a prospective method for cancer monitoring.
7. Create a surveillance resource that would list existing population-based cancer data for assessment of local or state cancer concerns (e.g., watershed information, demographics available from the census, and others).

Objective 3:

Broadly disseminate cancer surveillance findings to promote cancer awareness, policy development, and implementation of cancer control programs

Strategies:

1. Develop and maintain a master distribution list of cancer reports.
2. Create a list of Internet websites for cancer-related surveillance reports and articles pertaining to Maryland cancer statistics and information.
3. Share major surveillance reports and findings with the media.
4. Establish feedback mechanisms by which users of cancer surveillance system information can provide suggestions, including their unmet needs for information, and other comments.
5. Maintain, periodically revise, and continue to create informational materials about cancer surveillance.
6. Continue to distribute cancer surveillance documents, including reports and articles, to the appropriate audiences.

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CHAPTER 3

CANCER DISPARITIES

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CANCER DISPARITIES

Despite dramatic improvements in health in the United States over the last century, at no time in the history of the United States has the overall health status of racial/ethnic minority populations such as African Americans, Native Americans, Hispanics, and several Asian subgroups equaled that of white Americans.¹ Disparities in health are receiving increased national attention, and several major federal and local initiatives have been set up to define and reduce or eliminate disparities in health. While advances in health and medical care have produced improvements in longevity and health outcomes, there remain disproportionate disease burden and poorer health outcomes, or “health disparities” in the United States.^{2,3}

The term health disparities has been defined in several ways.⁴ For the purposes of this chapter, the committee developed the following definition, which is used throughout the chapter: “Health disparities are differences in the incidence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in Maryland.”

While racial/ethnic disparities in health are the largest category of disparities for which supportive data exist, disparities in other categories exist such as geography (urban vs. rural), gender (male vs. female), socioeconomic status (poor vs. non-poor), and age (elderly vs. non-elderly). It is important to note that racial/ethnic disparities may not be mutually exclusive of other disparity classifications. While many factors have been described as “causes” and are likely to be important in the genesis of disparities, scientifically validated evidence of definitive causal pathways and the underlying factors, such as biologic mechanisms, are poorly understood.^{5,6,7}

Cancer, the second leading cause of death in the United States, has documented racial/ethnic disparities which create a disproportionate burden for minority populations.^{8,9,10} The unequal burden of cancer in minority and underserved communities nationally and in Maryland is a crisis that requires intensive scientific research, community outreach, and translational activities that foster discovery and delivery of existing and new interventions to eliminate disparities. As such, the solutions to reduce and eliminate cancer disparities are complex and require intensive and multidisciplinary approaches that unite research and community outreach strategies.

Overview of Health Disparities

A substantial body of scientific literature documents racial/ethnic and low-income population differences in risk factors and exposures for behavioral, environmental, and other factors related to cancer disparities. This includes cigarette and smokeless tobacco use, alcohol consumption, diet and physical activity, and occupational and environmental exposures. (See chapters 5, 6, and 8.)

Disparities in health care access, utilization, and delivery are well established.¹¹ Access to, and delivery of, quality health care and differences in cancer screening and follow-up, as well as disparities in cancer treatment,¹² palliative care, and pain management¹³ are all factors related to racial/ethnic and geographic disparities in cancer rates. These health care factors may result in differences in cancer prognosis, stage, survival, mortality, and recurrence for minorities and the poor.

Health care delivery disparities have resulted in important national discussions as a result of a recent Institute of Medicine report.¹⁴ This report concludes that minorities, particularly African Americans, frequently receive lower quality of health care than whites, even when access-related factors are controlled.^{15,16,17,18} The sources of these disparities are complex and likely developed within the context of historic inequities, bias, clinical uncertainty, mistrust, personal behavior,

and the organization and operation of the current U.S. health care system.¹⁹

Disparities may occur in risk factors, exposures, and access and use of quality cancer services, which may result in higher cancer morbidity or incidence rates. Disparities in access to quality cancer and health care services may produce racial/ethnic differences in cancer outcomes, such as higher mortality or lower survival rates from certain cancers. This has been well-documented for African Americans compared to whites.^{20,21,22}

Data from the American Cancer Society, Centers for Disease Control and Prevention (CDC), National Cancer Institute (NCI) Surveillance Epidemiology and End Results (SEER) program, and North American Association of Central Cancer Registries document the existence of disparities in cancer incidence, mortality, and survival among different racial/ethnic groups, particularly for African Americans. Table 3.1 highlights cancer disparities among blacks and whites in incidence, mortality, and survival for select cancers in the United States.

From 1992 to 1999, African Americans were at a higher risk of developing and dying from cancer than any other racial or ethnic group.²³ During this time period, the age-adjusted cancer incidence rates for all sites combined among African Americans was 526.6 per 100,000 persons compared to rates of 480.4 for whites, 329.6 for Hispanics, 348.6 for Asian/Pacific Islanders, and 244.6 for American Indian/Alaska Natives.

Table 3.1
Black/White U.S. Cancer Incidence, Mortality, and Survival Rate Ratios

	Black/White Incidence Ratio (1995-1999)	Black/White Mortality Ratio (1995-1999)	Black/White Survival Rates (%) Ratio (1992-1999)
Breast (female)	0.88	1.32	.84
Lung	1.27	1.18	.82
Cervix	1.68	2.21	.84
Prostate	1.63	2.33	.95
Esophagus	1.78	1.80	.58
Stomach	1.96	2.23	.96
Liver	1.58	1.49	.68
Colon	1.12	1.36	.84
Oral cavity	1.19	1.71	.60

Source: Ries LAG, Eisner MP, Kosary CL, et al., editors. SEER Cancer Statistics Review, 1975-2000. Bethesda, MD: National Cancer Institute, 2003 (Accessed at http://seer.cancer.gov/csr/1975_2000).

Generally, whites have been the reference group in these epidemiological studies.²⁴ African-American males are the only group from any of the five racial and ethnic groups to have overall cancer incidence and mortality rates that are higher than overall cancer incidence and mortality rates for whites.

During the same time period, white females had the highest incidence of breast cancer, while African-American females had the highest mortality from breast cancer. African Americans had the highest incidence and mortality rates of all groups for colorectal, lung, and prostate cancer. The one exception to this rule were African-American females who had a slightly lower mortality rate from lung cancer than white females.

Among other racial and ethnic subpopulations, the following can be seen:

1. Cervical cancer incidence rates in Vietnamese women are five times higher than the rates among white American women (1988–1992).
2. Hispanic women had the second highest invasive cervical cancer incidence rates after Vietnamese women and twice the incidence rates of non-Hispanic white women.
3. Hawaiian women have the highest incidence and mortality from uterine cancer compared to other populations.
4. Alaska Natives have the highest incidence and mortality from colorectal cancer compared to all other populations except African-American males, whose mortality is slightly above that of Alaska Natives.²⁵

The remainder of this chapter is devoted to Maryland-specific health and cancer disparities. Maryland data, where available, will be provided for African Americans, Hispanics, Asian/Pacific Islanders, Native American/Alaska Natives, and whites. Major factors contributing to cancer disparities in Maryland are discussed, including geography, insurance status, socioeconomic status, and age. The chapter concludes with a discussion of some emerging special populations in the state and provides recommendations to reduce or eliminate cancer disparities in Maryland.

Classification of Race and Ethnicity

This chapter uses the standard federal classification of race and ethnicity referred to as “OMB Directive 15.” For more than 20 years, the standards in the federal Office of Management and Budget’s (OMB) Statistical Policy Directive No. 15 have provided a common language to promote uniformity and comparability for data on race and ethnicity for population groups. These standards were developed to provide consistent data on race and ethnicity throughout the federal government. Development of these data standards stemmed, in large measure, from new responsibilities to enforce civil rights laws. Data were needed to monitor equal access in housing, education, employment, and other areas for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity. The standards are used not only in the census (which provides the data for the “denominator” for many measures), but also in household surveys, on administrative forms (e.g., school registration and mortgage lending applications), and in medical and other research. The categories represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in this country and are not anthropologically or scientifically based.

The standards have five categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and white. There are two categories for data on ethnicity: “Hispanic or Latino” and “Not Hispanic or Latino.” The definitions of these categories is as follows:

- **American Indian or Alaska Native:** A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.
- **Asian:** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- **Black or African American:** A person having origins in any of the black racial groups of Africa. Terms such as “Haitian” or “Negro” can be used in addition to “Black or African American.”

- **Hispanic or Latino:** A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term “Spanish origin” can be used in addition to “Hispanic or Latino.”
- **Native Hawaiian or Other Pacific Islander:** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White:** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.²⁶

Cancer Disparities in Maryland

In Maryland, as in the United States, increasing attention is being placed on reducing and eliminating disparities in health. As on the national level, Maryland cancer disparities occur in a variety of categories including racial/ethnic, geographic, gender, age, and socioeconomic groups.²⁷ Disparities may exist for cancer incidence, survival, and mortality; socioeconomic status; risk factors such as occupational exposure, tobacco use, diet, nutrition and alcohol intake, physical activity, and family history; access and use of cancer prevention, screening, and early detection services; and treatment, pain management, and palliative care.^{28,29,30}

While major efforts are underway to define and describe disparities, the identification of specific factors that cause disparities and how these factors are interrelated is complex and poorly understood. Interventions to reduce or eliminate disparities are even more poorly understood. The following is a list of some major factors that may explain cancer disparities:

- risk factors and exposures (e.g., tobacco, alcohol, diet and physical activity, environment, and occupation)
- socioeconomic status
- discrimination
- knowledge, attitudes, and behaviors
- access to quality care
- low participation in clinical trials
- late stage at diagnosis
- delay in seeking diagnosis or treatment

- culture and language
- cancer care related behaviors, such as cancer screening and follow-up, early detection, treatment and palliative care, and pain management.
- other emerging factors, such as biology, prognostic factors, and co-morbidity

Racial and Ethnic Cancer Disparities in Maryland

Racial and ethnic minorities and underserved communities in Maryland suffer distinct disadvantages in accessing readily available health care services for cancer prevention, screening and follow up, early detection, and treatment.³¹ Historically, minorities and the poor have been under-represented in cancer research, particularly prevention research.³² Low representation in clinical trials and poor access to the benefits of cancer research are related to poor cancer outcomes. Racial/ethnic disparities in cancer incidence, mortality, and stage distribution in Maryland are found in Tables 3.2–3.8. Some rates are not available for Asian/Pacific Islanders, Hispanics/Latinos, and American Indians/Alaska Natives for some cancer sites due to 25 or fewer cases within the group. For the time period 1995–1999, the “other” category is used in some places as a combined indicator of smaller minority populations (American Indian, Asian, and Pacific Islander). Note that in these cases, the “other” group is not a homogenous population and contains subgroups that have different cancer rates.

Cancer Disparities in African Americans

African Americans in Maryland have the highest overall cancer incidence and mortality rates of any racial or ethnic groups (Table 3.2), as well as the highest incidence and mortality rates for many specific cancer sites, including the highest rates for colorectal, oral, and lung cancers. Cancer mortality is higher among blacks than whites for every cancer site; this is especially true for prostate and cervical cancer.

In general, African Americans are diagnosed with cancer at later stages than whites. Maryland whites have a higher proportion of localized disease at diagnosis than blacks, while blacks have higher regional and distant disease than whites (Table 3.4). Among whites, 43.3% of cancers are diagnosed in the localized stage compared to 34.8% for African Americans. There is higher localized disease in whites and higher distant disease

Table 3.2
Maryland Cancer Incidence and Mortality, All Sites Combined by Race and Ethnicity

Race/Ethnic Group	Dates	Overall Incidence	Overall Mortality
African American	1995-1999	527.6	276.9
White	1995-1999	492.9	210.3
Hispanic / Latino	1999	284.1	38.3
Asian / Pacific Islander	1998-1999	203.1	101.6
American Indian / Alaska Native	1998-1999	144.0	134.5

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry.

Table 3.3
Cancer Mortality Rates for Select Cancer Sites by Race in Maryland and the United States, 1995-1999

	MD Total	MD White	MD Black	U.S. Total
Lung and bronchus	62.5	61.3	72.5	57.7
Prostate	38.2	31.1	78.5	33.9
Female breast	31.2	29.8	38.3	28.8
Colorectal	24.3	22.9	31.9	21.7
Cervix	3.1	2.4	5.3	3.1

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: SEER, 1995-1999.

Table 3.4
Percent Distribution of New Cancer Cases by Stage at Diagnosis and Race in Maryland, 1999

Race	STAGE AT DIAGNOSIS		
	Localized (%)	Regional (%)	Distant (%)
MD Whites	43.3	20.9	16.1
MD Blacks	34.8	22.7	19.4

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1999.

Table 3.5
Lung Cancer Incidence and Mortality by Race in Maryland

Race/Ethnic Group	Dates	Incidence	Mortality
African American	1995–1999	82.4	72.5
White	1995–1999	77.4	61.3
Other*	1995–1999	41.3	22.0
Hispanic / Latino	1999	29.3	7.8
Asian / Pacific Islander	1998–1999	21.4	19.5
American Indian / Alaska Native	1998–1999	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry.

*Race reported as American Indian, Asian, and Pacific Islander are counted in the category called "Other."

Table 3.6
Colorectal Cancer Incidence and Mortality by Race in Maryland

Race/Ethnic Group	Dates	Incidence	Mortality
African American	1995–1999	66.0	31.9
White	1995–1999	57.0	22.9
Other*	1995–1999	50.0	11.7
Hispanic / Latino	1999	34.3	N/A
Asian / Pacific Islander	1998–1999	27.1	11.1
American Indian / Alaska Native	1998–1999	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry.

*Race reported as American Indian, Asian, and Pacific Islander are counted in the category called "Other."

Table 3.7
Female Breast Cancer Incidence and Mortality by Race in Maryland

Race/Ethnic Group	Dates	Incidence	Mortality
White	1995–1999	144.2	29.8
African American	1995–1999	128.6	38.3
Hispanic / Latino	1999	83.5	N/A
Asian / Pacific Islander	1998–1999	68.9	7.9
American Indian / Alaska Native	1998–1999	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry.

Table 3.8
Prostate Cancer Incidence and Mortality by Race in Maryland

Race/Ethnic Group	Dates	Incidence	Mortality
African American	1995–1999	255.0	78.5
White	1995–1999	158.4	31.1
Hispanic / Latino	1999	86.0	N/A
Asian / Pacific Islander	1998–1999	35.7	N/A
American Indian / Alaska Native	1998–1999	N/A	N/A

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry.

in blacks at the time of diagnosis for several types of cancer. For example, blacks with invasive cervical, breast, and prostate cancers are less likely to be diagnosed in Stages I or II than are whites.³³

African-American females have the highest incidence and mortality rates for cervical cancer. While white females have the highest overall breast cancer incidence rates, African-American females experience higher death rates from breast cancer than any other racial or ethnic group. Additionally, only 53.8% of African-American females are diagnosed in the most treatable stage of breast cancer, the local stage, compared to 62.9% of whites who are diagnosed at the local stage.

African-American males have the highest incidence and mortality rates and late-stage diagnosis for prostate cancer. They experience a considerable disparity in both prostate cancer incidence and mortality rates. The incidence of prostate cancer in African-American males is 1.6 times higher than that in white males, and mortality rates are over 2.5 times higher in African-American males than white males. Additionally, only 67.5% of African-American males are diagnosed at the local stage of prostate cancer, compared to 71.0% for whites.

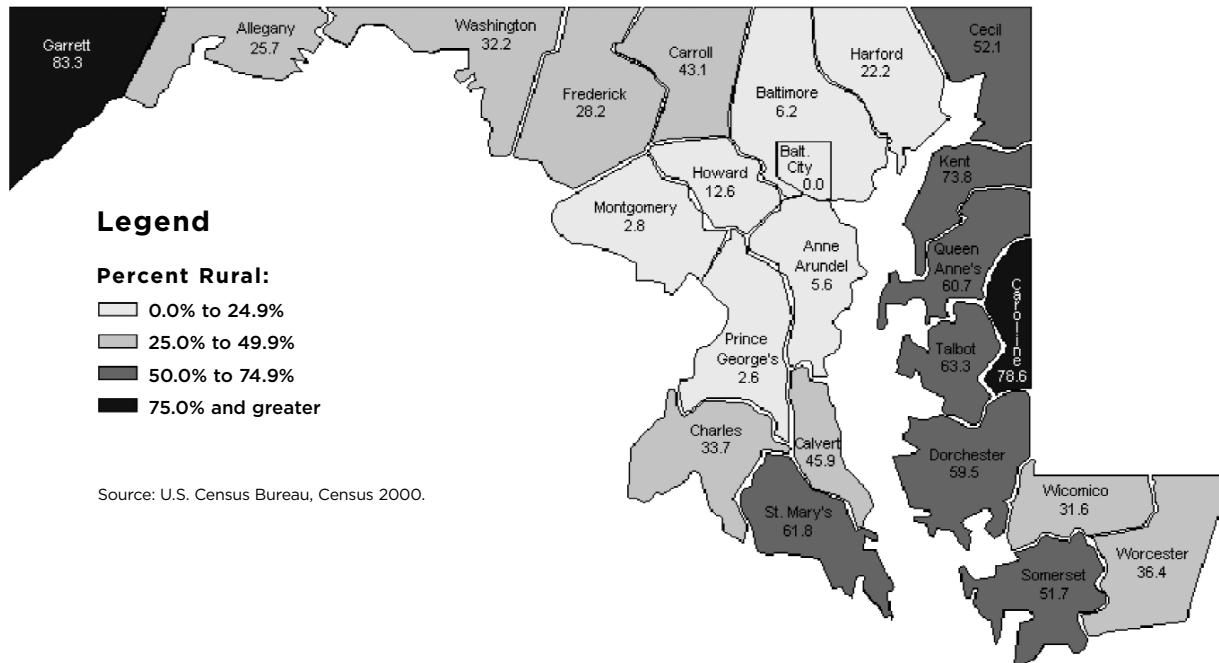
In Baltimore City, African Americans account for nearly 65% of the residents. Nearly a quarter of the population live in poverty, and the mortality rate for all cancers is the highest in the state—33% higher than the state cancer mortality rate. African Americans in Baltimore City have cancer mortality rates that are nearly 50% higher than the state cancer mortality rate.³⁴

Cancer Disparities in American Indian and Alaska Natives

Maryland has approximately 28 American Indian tribes, several of which are indigenous to the state. Despite having the lowest overall cancer incidence in Maryland, American Indian/Alaska Natives experience the third highest cancer mortality rate of all races/ethnic groups in the state. This population increased nearly 20% from 1990 to 2000, so surveillance and reporting is needed to provide a description of cancer in this population at the state level.

Cancer Disparities in Asian/Pacific Islanders

Asian/Pacific Islanders in Maryland experience lower overall and site-specific cancer incidence and mortality rates (where reported and/or available) compared with other racial/ethnic groups. However, Asian/Pacific Islanders are not a homogenous population and contain subgroups that have different cancer rates. One disparity for this population is evident in the stage of diagnosis for gender-based cancers—only 56.2% of female breast cancer cases are diagnosed in the most treatable, localized stage (1997–1998) while males diagnosed with prostate cancer fared better than the state average of 65.7% with 71.4% diagnosed in the localized stage.³⁵ Another apparent disparity is found in national data (1996–2000) that show higher death and incidence rates for certain cancers among this population. For example, this group experiences the highest incidence rates of liver and stomach cancer for both genders. This population increased more than 50% from 1990 to 2000, so surveillance and reporting is needed to provide a description of cancer in this population at the state level.

Figure 3.1**Percent Distribution of Maryland's Rural Population within Maryland Counties, 2000****Cancer Disparities in Hispanics/Latinos**

Although Hispanics/Latinos have lower cancer incidence and mortality rates overall compared with those of African Americans and whites, among minority populations they experience overall and site specific cancer incidence rates second only to African Americans. Hispanic/Latina females show disparity in the early diagnosis of breast cancer—only 50% are diagnosed in the most treatable, localized stage.³⁶

Considering the rapid population growth in this particular population, specifically an increase of 82.2% over the prior decade, there is concern for escalating health disparities within this population.

Racial/Ethnic Disparities in Cancer Screening and Treatment

In addition to higher cancer incidence and mortality and poorer survival rates from a number of malignancies, documented disparities in health services, cancer screening, and treatment in Maryland include the following:

- Despite high rates of “ever” being screened with mammography and Pap smears among African Americans in Baltimore City, low follow-up rates

for abnormal results contribute to late-stage diagnosis, higher mortality, and poor survival rates for African Americans with breast and cervical cancer.

- Cervical, breast, colorectal, and prostate cancers are excellent examples of disease sites in which cancer disparities exist in Maryland and nationally despite available screening methods.³⁷
- Treatment differences between black and white men for prostate cancer also exist.

Geographic Cancer Disparities in Maryland

Maryland is a geographically diverse state comprised of 23 counties and Baltimore City with a total land area of nearly 10,000 square miles. The population in Census 2000 was nearly 5.3 million residents, a 10% increase since 1990. The population ranges from nearly 900,000 in Montgomery County to approximately 650,000 in Baltimore City, with 30,000 residents in rural counties.

While Maryland is predominantly urban, nine of its twenty-three counties (nearly 40%) are predominately rural (i.e. more than 50% of the population is defined as rural by the U. S. Census Bureau). Overall, the state is 86% urban and 14% rural.³⁸ Figure 3.1 illustrates the rural percentages for each Maryland jurisdiction.

Maryland can be divided into five distinct regions: the Baltimore Metro region, the Eastern Shore region, the National Capital region, the Northwest region, and the Southern region.

The United States Census Bureau defines as “urban” all territories, populations, and housing units located within an urbanized area (UA) or an urban cluster (UC). It defines UA and UC boundaries as areas that encompass a densely settled territory, which consist of core census block groups or blocks that have a population density of at least 1,000 people per square mile, and surrounding census blocks that have an overall density of at least 500 people per square mile. “Rural” areas consist of all territories, populations, and housing units located outside of any UA and UC.

In 1987, the federal Office of Rural Health Policy (ORHP) was established to seek solutions to rural health care problems. Since 1999, ORHP has used the term “rural” to classify areas with populations of under 2,500. In Maryland, this federal designation includes Caroline, Dorchester, Kent, Somerset, Talbot, Wicomico, Worcester, St. Mary’s, and Garrett counties. The state classifies counties as rural based on their partially isolated locations, population size, and reduced access to resources and income.³⁹ This definition encompasses Cecil County on the Eastern Shore; Charles and Calvert counties in Southern Maryland; and Allegany and Washington counties in Western Maryland. In total, the federal or state definitions of “rural” cover all but Queen Anne’s County on the Eastern Shore, Southern Maryland, and Western Maryland. This chapter defines the Eastern Shore, Southern Maryland and Western Maryland as rural regions, and each county within these regions as a rural county.

Maryland’s rural population is 738,038 people, or 14% of the state’s population. The Eastern Shore is the largest rural region in the state. About eight out of every ten residents in two counties, Garrett County in Western Maryland and Caroline County on the Eastern Shore, are part of Maryland’s rural population.⁴⁰

Central Maryland (i.e. the Baltimore Metro and National Capital regions) is predominantly urban and includes urban Baltimore City. Identifying populations as urban and rural are essential since geography presents unique circumstances and factors that hinder health care access, education, and policy.

The racial distribution of Maryland is 64% white, 27.9% African American, and the remainder of the population is Asian, Hispanic, and American Indian. Baltimore City has a population that is 65% African American and a poverty rate of approximately 22.9%. On the Eastern Shore, 80% of the population is white; in Southern Maryland, 77% of the population is white; and in Western Maryland, 91% of the population is white.

Populations from rural counties experience health disparities based on the partially isolated locations, reduced access to resources and income, and population size. Table 3.9 presents data on Maryland’s rural and underserved populations. Nearly half (7 of 15) of the counties in rural Maryland have poverty rates exceeding 10%. Somerset County, where one out of every five persons lives in poverty, has the highest poverty level in the state. The Maryland Health Care Commission reports that 38% of Maryland residents living below the federal poverty level have no private or public health insurance. From 1996 to 2001, one out of every five individuals in Caroline, Somerset, and Garrett counties had no health insurance. Eight of the twelve remaining counties in rural Maryland had uninsured rates exceeding ten percent.⁴¹ Of particular attention is Somerset County, the poorest county in the state, which is second only to Baltimore City in cancer mortality rates and leads the state in lung cancer mortality rates.

Barriers to cancer prevention, detection, diagnosis, and treatment exist in Maryland’s rural and urban communities. Rural communities have high rates of uninsured residents and have high numbers of elderly residents, lack public transportation, and lack access to primary and specialty health care. Urban areas also have transportation barriers (especially for senior citizens), high Medicaid rates, and cultural and linguistic barriers. Some Eastern Shore counties, such as Somerset and Caroline counties, which have higher numbers of African-American and migrant seasonal workers, respectively, also have cultural and linguistic barriers.

While Maryland is a diverse state, data on geographic disparities within race/ethnicity groups have focused on the two largest racial segments of the population, African Americans and whites. Currently, the Maryland Cancer Registry (MCR) collects data for the smaller population groups, but often the numbers within various geographic regions are too small to calculate accurate cancer statistics. Thus, within the discussion of geographic disparities, cancer disparities for

Table 3.9
Rural and Underserved Populations in Maryland

County	Population (#)	RURAL (#)	Age 65+ (%)	Poverty (%)	Medical Assistance (#)	No Health Care Coverage#	MUA/P	PC HPSA	MH HPSA	Den HPSA
MARYLAND	5,296,486	737,818	11.3%	8.5%	624,942	~	~	~	~	~
Allegany	74,930	19,245	17.9%	14.8%	11,170	14.5%	Yes	Yes	NA	Yes
Calvert	74,563	34,235	13.2%	4.4%	6,373	8.5%	Yes	Yes	NA	NA
Caroline	29,722	23,403	13.5%	11.7%	5,336	20.9%	Yes	Yes	NA	Pending
Cecil	85,951	44,804	10.5%	7.2%	10,516	12.0%	NA	Yes	NA	NA
Charles	120,546	40,644	7.8%	5.5%	12,614	8.4%	Yes*	NA	NA	Yes*
Dorchester	30,674	18,262	17.7%	13.8%	6,013	14.1%	Yes	Yes	Yes	NA
Garrett	29,846	24,848	14.9%	13.3%	5,952	23.7%	Yes	Yes	Yes	Yes
Kent	19,197	14,162	19.3%	13.0%	2,497	14.3%	Pending	Yes	Yes	Pending
Queen Anne's	40,563	24,632	12.9%	6.3%	3,717	11.1%	Yes*	Yes*	NA	Pending
St. Mary's	86,211	53,238	9.1%	7.2%	9,096	9.2%	Yes	NA	NA	NA
Somerset	24,747	12,791	14.2%	20.1%	4,513	19.4%	Yes	Yes	Yes	Yes
Talbot	33,812	21,394	14.2%	8.3%	3,776	8.6%	Yes*	NA	NA	NA
Washington	131,923	42,499	14.2%	9.5%	15,567	14.1%	Yes*	Yes*	NA	NA
Wicomico	84,644	26,777	12.8%	12.8%	14,007	13.0%	Yes*	Yes*	NA	Yes*
Worcester	46,543	16,950	20.1%	9.6%	6,468	13.1%	Yes	Yes	Yes	Yes
Baltimore City	651,154	0	17.9%	22.9%	195,847	17.3%	Yes*	Yes*	Yes*	Yes*

MUA/P: Medically underserved area for primary care.

PC HPSA: Primary care health professional shortage area.

MH HPSA: Mental health professional shortage area.

Den HPSA: Dental professional shortage area.

#: Based on CDC five-year average.

#: See individual counties for MUA/P and HPSA designations.

*: Only partial areas of county designated as MUA/P and primary care, mental health, and dental HPSAs.

Source: U.S. Census Bureau, Census 2000.

Table 3.10
Cancer Mortality Rates for Maryland and Select Maryland Regions
for All Cancer Sites, Races, and Sexes Combined, 1995–1999

	Total	Males	Females
Maryland Total	220.3	278.1	184.3
Maryland White	210.3	261.1	179.5
Maryland Black	276.9	377.2	214.2
Southern region	229.3	283.9	191.1
Eastern Shore region	229.4	291.2	187.2
Western Maryland region	203.0	258.1	165.9
Baltimore Metro region	215.8	268.8	183.7
Baltimore City	293.8	392.8	234.3

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: NCI SEER, 1995–1999.

blacks and whites are highlighted.

Table 3.10 demonstrates select Maryland cancer mortality disparities for African Americans and whites and for selected geographic regions, including rural regions, of the state. Age-adjusted mortality rates for all sites are higher in Baltimore City, the Baltimore Metro area, the Eastern Shore, and Southern Maryland than in the state as a whole.

Baltimore City leads the state in cancer mortality rates for all races combined (293.8) and for African Americans (322.3). Prince George's County follows in all cancer mortality for African Americans (297.2), with Baltimore County in third place (288.4). Collectively these three counties comprise nearly three-quarters of the African-American population in Maryland. Additionally, African-American females in the following three regions experience higher mortality rates than any other race/ethnicity reported in any Maryland county: Prince George's (44.1), Baltimore City (40.9), and Montgomery County (39.8).

The rural areas of Maryland (i.e. Western Maryland, Southern Maryland and the Eastern Shore) generally have geographic disparities resulting from a health system infrastructure characterized by fewer health resources and greater travel distances to those resources, a lack of private and public transportation, and higher percentages of poor and uninsured citizens. In some rural regions, agricultural exposures to pesticides, water environmental hazards, and other rural

industries may play a role in cancer incidence and mortality. These factors require additional research to determine their role in cancer causation.

Urban geographic factors include poor air quality, in particular, the presence of Hazardous Air Pollutants (HAPs). HAPs are chemicals that can cause adverse effects to health or the environment and include chemicals that can cause cancer. Maryland ranks sixth worst in the nation for hazardous air pollutants.

Baltimore City has disparagingly high cancer rates, along with a disproportionate rate of uninsured or underinsured minority population (especially those aged 65 and older). The rural regions of Maryland have greater percentages of individuals aged 65 and older.

Insurance Status and Cancer Disparities

Health insurance status is a strong predictor of access to health care.^{42,43,44,45,46,47} Persons with health insurance are almost twice as likely to seek an annual physical, including cancer prevention and screening, than persons without health insurance.^{48,49,50} The number of uninsured Americans has increased from the 1980s through 2000. Current estimates of the percentage of uninsured persons under age 65 in Maryland vary from 10% to 14%, as shown in Table 3.11.^{51,52}

Racial and ethnic minorities in Maryland are twice as

Table 3.11
Percent of Uninsured Persons in Maryland and the United States, 1998 and 2000

Source	Year	Uninsured in Maryland	Uninsured in United States
U.S. Census Bureau: Current Population Reports	2000	9.9%	14.0%
Behavioral Risk Factor Surveillance System	1998	13.6%	13.0%

Source: United States Census Bureau, 2000; CDC BRFSS, 1998.

likely as white, non-Hispanic residents to be uninsured. Minority groups comprise a higher percentage of the uninsured at all income levels.⁵³ In Baltimore City, an estimated 25% of residents do not have health insurance, and in certain segments of Baltimore City, adult males may have an uninsured rate that exceeds 50%.⁵⁴

One study found that elderly insured persons were more than 1.5 times more likely to seek breast, cervical, and colorectal cancer screening services than the uninsured.⁵⁵ Mammography screening and adherence to recommended mammography follow-up in older women are influenced by several socioeconomic factors, including insured/uninsured status.^{56,57} Analysis of data collected from more than 28,000 patients in Florida in 1994 and data from a survey in North Carolina showed that uninsured persons were more likely than insured patients to be diagnosed with later stages of colorectal, melanoma, breast, and prostate cancers.^{58,59}

Socioeconomic Status and Cancer Disparities

Socioeconomic status (SES) is one of the major determinants of health.⁶⁰ According to the U.S. Department of Health and Human Service's Healthy People 2010 report,⁶¹ higher socioeconomic groups experienced greater health gains compared to lower socioeconomic groups. Lower SES has been associated with higher cancer risk behaviors as well as poorer cancer outcomes, particularly for cancers of the breast, colon, and prostate.^{62,63,64} Cancer mortality rates in the United States are significantly higher in the lower socioeconomic groups.⁶⁵ Furthermore, higher educational attainment and income among African Americans has been more positively associated with reductions in smoking among black men than white men.⁶⁶

Contributing factors associated with lower SES may include lower educational level, culture, ethnic/cultural beliefs, and access to adequate health care.

Although overall cancer mortality showed a steady decrease from 1995 to 1999 throughout the state, ethnic and racial minorities continue to demonstrate significant cancer disparities throughout Maryland. SES as a major contributor to health status and cancer disparities must be addressed as part of a comprehensive approach to eliminate cancer disparities throughout the state.

Age and Cancer Disparities

The majority of cancers in the United States occur in people aged 65 and over.⁶⁷ Elderly cancer patients, in particular those patients who are over age 65, experience documented disparities in cancer screening and risk reduction interventions⁶⁸ and clinical trials participation.⁶⁹ Senior citizens (i.e. individuals 65 years and older) make up only 11.3% of Maryland's population; however, seven out of every ten cancer deaths are from this age group.

The Disabled and The Mentally Ill

There are several definitions of disability. The National Center for Health Statistics (NCHS) defines disability as a "limitation of activity due to chronic conditions." The World Health Organization's International Classification of Impairments, Disabilities and Handicaps (ICIDH) defines disability according to functional performance and activity measures.⁷⁰ For the purposes of this chapter, disability is defined as having a physical or mental impairment that limits function or restriction in one or more major life activities,

in accordance with the Americans with Disabilities Act.⁷¹ In this manner, those individuals whose impairments were consequent to a mental, emotional, or physical health condition with limited to severe functional ability, mobility, and self-care are included.

Among Maryland residents, there are 86,500 developmentally disabled persons, 467,364 physically disabled persons (not inclusive of children under the age of 15), and 76,000 persons with severe mental illness.⁷² The disabled population is diverse, crossing all geographic, racial/ethnic, sex, educational, and socioeconomic lines. It also consists of persons from various mental and physical chronic disease strata.

Disability is frequently listed as an indicator in health disparity definitions.⁷³ Yet, there is limited data to implicate physical or mental limitations solely as a cause of health disparities. Most often the vocational, economic, and educational disadvantages experienced by persons with disabilities are what leads to inequity in receiving adequate and equal health care.

Chronic diseases such as cancer, arthritis, high blood pressure, heart disease, diabetes, and substance abuse affect people with disabilities just as they do the general population, but they may have unique implications for the health of people with disabilities.⁷⁴ Cancer statistics and behavioral risk factor information for the disabled are not currently available. However, studies have indicated that women with physical disabilities reported chronic conditions more than the comparison group without disabilities and at younger ages,⁷⁵ and that people with mental illness also tend to be in worse physical health and to have more chronic conditions than those with no disorders.⁷⁶

Data on cancer screening prevalence among persons with disabilities is also limited. A supplemental report to the National Health Interview Survey (NHIS) found that women with functional limitations are less likely to receive Pap tests and mammograms than women who are not disabled. This report further suggests that the probability of receiving screening exams decreases among older women and among women with more severe disabling conditions. While studies to correlate later stage diagnosis of breast cancer among women with disabilities are conflicting, it is known that women aged 65 or older who had three or more functional limitations were significantly less likely to have had a mammogram than non-disabled women in the same age range.⁷⁷ Research indicates that the presence of a disability may make it difficult to deliver women's

cancer screening exams and may cause secondary complications that could impair functioning.^{78,79} Women with a physical disability face multiple barriers in access to adequate cancer screening. Some of these barriers include refusal of treatment by health care providers because of the presence of a disability, the assumption that a disabling condition precludes sexual activity and therefore decreases the likelihood of cervical cancer, the unavailability of appropriate examination tables, and a lack of mammography facilities and mobile units that can accommodate the needs of the physically disabled.⁸⁰

Characteristics associated with poorer health status previously mentioned in this report, such as race/ethnicity, geography, insurance coverage, and age may compound cancer disparity issues among the disabled.

Nationally, individuals with disabilities are less likely to have adequate health care coverage. Among those aged 25 to 64, persons with a severe disability are more likely to lack any form of health insurance than those with no disability. In 1997, 82.3% of non-disabled persons aged 25 to 64 were covered by private health insurance compared to 47.5% of severely disabled persons of the same age. Private insurance coverage for those persons 65 years and older with a severe disability versus no disability were 67.0% and 79.7%, respectively.⁸¹

In addition, the probability of having a disabling condition often increases with racial or ethnic minority status. American Indians and African Americans have the highest disability rates at 23.9% and 21.6%, respectively.⁸² Of persons aged 15 to 64, 7.4% of whites have severe disabilities compared to 12.7% of African Americans and 9.1% of Hispanics/Latinos.⁸³

The likelihood of having a disability increases with age. Of the physically disabled in Maryland, about 170,000 (13%) are 65 years of age or older who reportedly have some sort of mobility or self-care disability.⁸⁴

Additionally, mental illness is very common in the United States. Millions of people experience at least one disorder at some point in their lifetime, and a significant number of people experience more than one. There is a negative stigma associated with having a mental illness, which in and of itself can be disabling. Consequently, the shame and embarrassment experienced by persons with a mental illness may keep some from seeking needed treatment.

Gay, Lesbian, Bisexual, and Transgender Populations

Cancer disparity issues for the gay, lesbian, bisexual, and transgender (GLBT) populations are poorly understood due to lack of data collection and reporting. While data are not available on disparities for these populations, empirical information suggests that disparity issues faced by the GLBT population include physician bias, unequal treatment and/or coverage for health care, and stress arising from being exposed to and confronted by homophobia within the health care system.

Data from the Mautner Project suggest that lesbians receive routine gynecological screening less frequently than their heterosexual counterparts and that they are more likely to be childless or delay childbearing until after the age of 30. Nulliparity and late age at first birth have been associated with a higher risk of female breast cancer.⁸⁵

Previous negative encounters with the health care system, fear of disclosure of GLBT identity, and exclusion from health promotion campaigns all play a role in GLBT persons not accessing health care.⁸⁶ If GLBT people remain closeted to their health care providers, they may not be given important information that could help them remain healthy.⁸⁷ The ability to appropriately address cancer prevention and control needs for these communities requires formal, quality data collection and reporting and the training of health care professionals in GLBT cultural competency.



Cancer Disparities Goals, Objectives and Strategies

Goal:

Reduce cancer health disparities in Maryland.

Target for Change

By 2008, develop a system to monitor and document cancer disparities in Maryland.

Objective 1:

Increase public and community awareness about cancer health disparities and cancer prevention, screening, and treatment in Maryland.

Strategies:

1. Collaborate with government agencies, academic health centers, community and faith-based organizations, and private foundations to educate the public about topics relating to health disparities and cancer, including:
 - the importance of social, economic, cultural, and environmental factors in influencing personal and community health.
 - the role of behavioral and biological factors in determining cancer risk.
 - types of current interventions that can reduce/modify risks for developing cancer or the progression of cancer.
2. Disseminate current and accurate information about cancer prevention, screening, early detection, and treatment, including complementary and alternative therapies to minority and underserved populations in Maryland.
 - Identify “Best Practices” for health communication and interventions for specific minority and underserved populations, in order to improve approaches and effectiveness of resources.
 - Utilize existing educational resources, such as the Cancer Survival Toolbox,⁸⁸ and modify as appropriate to educate community members in a variety of settings including health care, schools, social, and faith-based institutions.

**Objective 2:**

Develop and implement health care programs designed to reduce cancer disparities among targeted populations in Maryland.

Strategies:

1. Adapt the Community Health Worker (CHW) model for use in a variety of settings in Maryland to address barriers to access, culturally therapeutic compliance, services utilization, cancer risk management, and health education.
2. Work in partnership with local Community Health Centers and Area Health Education Centers to develop cancer prevention, screening, and treatment programs aimed at disparate populations.
3. Link U.S. military veterans with cancer prevention, screening, and treatment services within the Veterans Affairs health care system.
4. Implement in Maryland the Department of Health and Human Services standards for Culturally and Linguistically Appropriate Services (CLAS),⁸⁹ including availability of interpretation services.
5. Foster development and implementation of “National and Maryland Models that Work” to reduce and eliminate cancer disparities in targeted populations.
6. Collaborate with the Maryland Special Populations Cancer Research Network, National Cancer Institute, and NMA, to increase the number of minority and underserved health care professionals including researchers involved in cancer research.

Objective 3:

Increase cancer disparities documentation and intervention on a systematic basis in Maryland.

Strategies:

1. Support ongoing surveillance efforts and disparities research
2. Produce a status report on cancer disparities in Maryland every two years and disseminate the report to key stakeholders including communities, media, health care and social service organizations, and policy makers.
3. Expand and enforce cancer data collection and reporting on racial/ethnic minorities based on the Office of Management and Budget (OMB) categories and use sub-population groups where possible.⁹⁰ This includes a Maryland uniform method of recording race/ethnicity for all hospitals and other health care facilities that are required to report to the Maryland Cancer Registry.
4. Expand cancer data collection in the Maryland Cancer Registry to include level of education, socioeconomic status, and primary language.⁹¹
5. Provide technical assistance to community-based watch groups that monitor industrial and commercial environments.
6. Expand data collection regarding emerging populations of concern for cancer disparities, including the disabled and mentally ill and GLBT populations.

**Objective 4:**

Increase provider education and reimbursement aimed at reducing cancer disparities.

Strategies:

1. Require educational modules on cancer prevention, education, screening, and treatment for disparate populations and provide training on cultural diversity and barriers to reaching medically underserved populations for health professional students as part of their clinical rotation.
2. Collaborate with the National Cancer Institute, Maryland cancer centers, regionally recognized medical centers, and Area Health Education Centers to develop continuing education programs for health care professionals in medically underserved and rural areas on cutting edge cancer prevention, screening, and treatment methods.
3. Provide reimbursement incentives for primary care providers to increase prevention, screening, and treatment services to high-risk groups, including Medicaid incentives for primary care practitioners that refer patients for cancer prevention, screening, and treatment services.

Objective 5:

Improve access to, and utilization of, cancer screening and treatment options for underserved populations.

Strategies:

1. Advocate for lowered costs of chemotherapy and other cancer treatments for low-income and uninsured or underinsured populations.
2. Increase patient education and access to participation in high-quality clinical trials for low-income and uninsured or underinsured populations.
3. Advocate for consistency of benefits and protections for publicly funded HMO enrollees to be the same as private HMO enrollees.⁹²
4. Promote the consistency and equity of care through the use of evidence-based guidelines, and structure pay systems to ensure an adequate supply of health care services to minority and underserved populations.⁹³

Objective 6:

Improve the quality of cancer care received by racial/ethnic minorities.

Strategies:

1. Foster research on Maryland disparities in quality cancer care.
2. Support health professional continuing education on quality cancer care guidelines, particularly for cancers where disparities are most pronounced.
3. Disseminate cancer care guidelines to the general public via websites, portals, or other mechanisms.
4. Foster activities which improve the delivery of quality cancer care.

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CHAPTER 4

PATIENT ISSUES AND CANCER SURVIVORSHIP

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PATIENT ISSUES AND CANCER SURVIVORSHIP

It is because so many people must deal with the challenge of facing a life threatening disease—cancer—that so many have worked so diligently to develop this cancer plan. We must never lose sight of the fact that the sole purpose of our research to find better ways to prevent, detect, and treat cancer is to promote patient care and to help those who face a cancer diagnosis. We must continually strive to improve the manner in which we deliver that care to the public. If the science is not translated into widespread patient care then the science becomes irrelevant.

No matter what the type of cancer, each person with a cancer diagnosis deals with a myriad of difficult issues that affect their lives, the lives of their loved ones, and their chances for survival. The issues that confront cancer patients cut across all diagnoses, all cultures, all demographics, and all situations. The goal of this chapter is to identify problems faced by cancer survivors in Maryland and to recommend solutions to those prob-

lems. This chapter defines “cancer survivor” as someone living with, through, or beyond cancer from the moment of diagnosis. This definition was first developed by the National Coalition for Cancer Survivorship,¹ and has been adopted by many organizations including the National Cancer Institute² and the Lance Armstrong Foundation.³ Because family members, friends, and caregivers are also impacted by the survivorship experience, they are included in this definition.

This chapter identifies four major problem areas faced by cancer survivors. They are:

- Access to information and resources
- Financial and legal issues
- Psychosocial issues
- Long-term survivorship

Because these areas of concern are multifaceted, complicated, overwhelming, and numerous, an ongoing Patient Issues and Cancer Survivorship Advisory Board should be formed to oversee the implementation of the recommendations within this chapter and to continue to examine the issues and expand upon the findings of the Patient Issues and Cancer Survivorship committee.

Access to Information and Resources

“You have cancer” is one of the most overwhelming and frightening phrases anyone can be confronted with. That phrase raises immediate and confusing questions such as:

- Whom should I call?
- Will I die?
- What kind of treatment should I have?
- What are my options?
- Should I get other opinions?
- Who will take care of me?
- Where do I get the information that I need to answer all of these concerns?

Unfortunately, it is often very difficult for patients to receive and understand information pertaining to their cancer diagnosis. There is a great need for education and assistance with the cancer decision-making process. According to the National Adult Literacy Survey (NALS), 21–23% of adults demonstrated literacy skills in the lowest level of proficiency (Level 1).⁴ Though many factors contribute to the large number of surveyed adults demonstrating the lowest proficiency level, it remains that many adults may lack the literacy and skills necessary to understand and make decisions about their health and well-being.^{5,6} In addition, the percentage of the population whose first language is not English is increasing; in Maryland in 2000, 12.9% of adults spoke a non-English language at home, up from 9% in 1990.^{7,8} Non-English speaking patients need assistance with information given to them by medical professionals, but this is not always afforded them.⁹

Patients with low literacy levels and who may not speak English are not the only ones who experience difficulty understanding medical information related to their cancer diagnosis and treatment. In one study of hospitalized cancer patients, 74% of patients reported that they would have liked more information about their future condition, and over 50% reported that they had unmet needs regarding information about their diagnosis, exams, and treatment.¹⁰ This gap in information may stem in part from communication problems between patients and medical staff, a barrier cited by the vast majority of cancer patients in another study sample.¹¹

Unmet needs for information and assistance in understanding one's own medical situation often lead the patient to non-adherence with the recommended treatment and follow-up. In addition, a lack of information and understanding contributes negatively to patients' quality of life and increases anxiety

about their condition.¹²

Various methods have been successfully utilized to assist cancer patients in receiving the information and educational assistance they need. Oftentimes health care providers do not have the time or expertise in all the areas that affect their patients and their families to provide them with the information and help that they require. Cancer information hotlines have been used on a national, state, and local basis for some time in an effort to supplement scanty information given to patients by health care providers. The American Cancer Society and the National Cancer Institute's Cancer Information Service (CIS) operate national hotlines and can provide patients with virtually unlimited cancer information and resources. The CIS collects data on the types of callers and reasons for calls to its hotline, and through evaluation efforts has confirmed the great "health education potential of telephone helplines."¹³

Another well-documented intervention for increasing access to information as well as patient adherence is the use of a patient navigator, or case manager, is typically an outreach worker who monitors the patient's needs and ensures he or she receives appropriate care. Navigator systems were originally designed to aid in follow-up of abnormal screening results for breast and cervical cancers. However, the navigator concept is increasingly being expanded to include follow-up of abnormal results for screening tests performed for other cancer sites such as prostate and colorectal. In addition, navigator systems may well be used before any screening has occurred in an effort to reduce cancer risk behaviors and steer the patient into screening, as well as to guide the patient through treatment and the accompanying decision-making processes. For example, in one study of men in Georgia, receiving a client navigator intervention was one of the most important predictors of men participating in a free prostate cancer screening.¹⁴ In another study of medically underserved women with abnormal breast findings, 87.5% completed recommended breast biopsies when the patient navigator intervention was employed. Only 56.6% of patients received the recommended biopsy when they did not receive patient navigation.¹⁵

Regardless of the methods used to achieve awareness and strengthen education, the citizens of Maryland need readily available information in order to take charge of their health care needs in general as well as

their needs in relationship to cancer in particular. Not only should they be educated about preventative behaviors, available screenings, and signs and symptoms, they must be afforded easy access to timely information and resources for decision-making pertaining to diagnosis and treatment, financial and legal issues, psychosocial issues, and long-term survivorship. Comprehensive information on all possible treatment options, clinical trials, second opinions, repercussions of treatment and disease, and available support and resources should be readily available to all cancer patients and their loved ones.

Financial and Legal Issues

Another area of concern for people affected by cancer relates to financial and legal issues. Once medical decisions have been made and treatment has begun, there are many practical issues that must be addressed. A cancer diagnosis puts many stresses on a person beyond the physical. The process of treatment and recuperation is a very expensive one. More questions arise, such as:

- How will I pay for my treatment?
- Do I have health insurance coverage? Is it comprehensive? What about life insurance?
- How will I pay for co-pays and medications?
- How will I get transportation to my treatment centers?
- How will I pay for child care?
- Will I lose my job?
- Will I be able to go back to work? Will I need a different job?

The NIH estimates that overall costs for cancer in the year 2002 were \$171.6 billion: \$60.9 billion for direct medical costs (total of all health expenditures); \$15.5 billion for indirect morbidity costs (cost of lost productivity due to illness); and \$95.2 billion for indirect mortality costs (cost of lost productivity due to premature death).¹⁶

In addition to the direct cost of medical care and wages lost due to illness, the financial burden on cancer patients is exacerbated due to increased out-of-pocket expenses. Even those with insurance can be devastated by elevated expenses associated with high deductibles and co-payments, transportation, child and elder care, home care expenses, special foods or equipment, and

compounded by lost wages.^{17,18} One study found transportation and food to be the largest out-of-pocket expenses for patients receiving outpatient chemotherapy.¹⁹ With more and more health care being delivered on an outpatient basis, patients must routinely make arrangements for transportation to treatment. Transportation has been found to be a major barrier to receiving care, particularly for minority patients, and often causes some patients to forgo necessary cancer treatment.²⁰ This issue is of great importance in Maryland. During each of the seven comprehensive cancer control Town Hall Meetings held at various sites throughout Maryland during the summer of 2002, a lack of transportation was cited as a major barrier to accessing cancer services.²¹

In addition to the financial burden of medical care and associated out-of-pocket expenses, cancer survivors may experience long-term financial and legal difficulties stemming from disability and other problems associated with returning to work. Despite the fact that many states have an increased focus on vocational rehabilitation for cancer patients,²² “approximately 25% of Americans with a history of cancer experience disparate treatment in employment solely because of their medical histories.”²³ Much of the discrimination likely results from employers’ lack of understanding of the variability in prognosis of the many types of cancer and misconceptions about the productivity of cancer survivors in relation to other workers.^{24,25} In one study, problems reported by breast cancer survivors upon returning to work included job loss, demotion, unwanted changes in tasks, problems with the employer or co-workers, personal changes in attitudes to work, and diminished physical capacity.²⁶ While confronting all of these issues, the quality of life of a cancer survivor may be severely impacted when he or she does not change jobs because of the fear of losing his or her health insurance, of discrimination, or of the ability to obtain a new job.

Many cancer patients need health services that are not routinely considered part of their treatment, which is another aspect of the financial burden confronting cancer survivors. The most significant of these is the need for mental health services, which will be discussed in the next section. Other services that cancer patients may need include fertility treatment (or arrangement for sperm or egg storage) and physical or occupational therapy. Though cancer is commonly viewed as a disease of the elderly, increasing numbers of cancer patients are of child-bearing age. Cancer patients don’t always receive timely information regarding fertility

services thus many patients do not consider this factor as they make treatment decisions. In addition, fertility services can be very expensive and are not often covered by insurance, even for cancer survivors whose fertility may have been affected by necessary medical treatments. Physical and occupational therapy are more likely to be covered by insurance, but again, patients often do not receive appropriate and timely information regarding these services. In many cases, a referral is required for the therapy to be covered by the patient's insurance and this may present a barrier to the patient obtaining the therapy.

Lack of health insurance and other financial barriers may prevent Marylanders from receiving optimal cancer care.²⁷ The financial burden may cause cancer patients to face setbacks in treatment adherence, overall functioning capacity, and quality of life.²⁸ Regardless of socioeconomic status, almost all families confronted with cancer and its treatment will experience financial difficulties.²⁹ New and creative methods must be developed to reduce the devastating financial burden of cancer on Maryland families.

Psychosocial Issues

Along with a cancer diagnosis automatically comes a wide range of emotions including, but not limited to, fear, anger, depression, shock, confusion, and denial, as well as optimism and hopefulness. Some of the psychosocial concerns that arise are:

- Will my doctors understand my feelings and stresses?
- Will I die?
- Where can I get help dealing with my feelings? How will I pay for these services?
- How will I interact with my family, friends, and co-workers?
- How will I deal with losing my hair, or having scars or burns?
- How will I cope with side effects?
- Will I lose my independence?
- Will my cancer reoccur?

Cancer survivors deal with many stresses that could be partially or completely alleviated with the help of psychosocial support services, including support groups, mental health counseling, and the support of trained

professionals such as social workers, professional counselors, psychologists, and psychiatric nurses. These services may be used alone or in combination, depending on the patient's needs. These support services may aid a cancer patient and his or her family in understanding changes in family, social, work, and school relationships, changes in body image and physical capacity, emotions such as depression, anger, and fear, feelings associated with loss of control and independence, memory loss, and the cognitive effects of treatment and medication. Support services may be helpful in a variety of settings, including professionally led support groups, one-on-one peer support programs, patient education conferences, and even electronically-based support groups; participation in any of these support services has been shown to reduce anxiety and depression and generally improve quality of life for cancer survivors.^{30,31,32,33} Electronically-based support programs may be especially important for rural or other populations without access to in-person support groups.³⁴

Patients are often reluctant to communicate their psychological and emotional concerns to their physicians or other medical practitioners. This reluctance may stem from the stigma associated with seeking and receiving counseling, a lack of awareness of psychosocial support services, or many other factors. Many medical practitioners do not see their patients often throughout the treatment phase and therefore are not fully aware of the psychological stresses their patients are dealing with. In addition, health care providers are often accused of not being sensitive to the psychological needs of their patients. Further, some health care practitioners do not routinely refer their patients and their families to mental health professionals and services. One study found a direct correlation between the attitudes of health care providers toward cancer support services and referrals given to their patients for psychosocial support services.³⁵ The study suggests that assembling a concise directory of locally available resources and improving collaboration among agencies may help to improve provider referrals to support services.³⁶

Additional provider education may also be necessary to give health care professionals the necessary understanding and appreciation of the cancer survivor's needs. A curriculum entitled "Bearing Witness to Cancer" has been developed at Brown University's Department of Community Health.³⁷ The course explores the experiences and issues faced by people dealing with cancer using a biopsychosocial framework, and is open to students in a variety of disciplines

at various academic levels. In addition to instituting similar curricula in Maryland universities, educational offerings should be expanded for currently practicing health care providers. Barriers to providing psychosocial training for providers include the skepticism among health care professionals about its usefulness,³⁸ as well as the time required to provide effective psychosocial care.³⁹ While many providers, especially nurses, do acknowledge the importance of the psychosocial aspects of care, many do not express confidence and adequate skill level for delivering this type of care.⁴⁰ Various methods of continuing education have been shown to increase the confidence, knowledge, and skills of the participants in managing the psychosocial issues of cancer patients.^{41,42}

Certainly, specific “improvements are needed in recognizing mental health problems among cancer survivors and reducing barriers to psychosocial service use.”⁴³ Compared with individuals without a cancer history, cancer survivors reported significantly greater contact in the past year with a mental health provider.⁴⁴ However, many individuals do not understand how mental health services could help them, or the range of services that may be available to them. Also, there are stigmas attached to seeking and receiving mental health care among some cultures and populations. Patients may be embarrassed or fearful of seeking such help. Indeed, stigma is one of the most common barriers to accessing mental health services cited throughout scientific literature.⁴⁵ For those that do seek mental health services, access is restricted by the availability of trained providers. A survey of providers recently completed by the Maryland Mental Health Coalition found that over the last five years, 76% of those surveyed reported increased difficulty accessing mental health services for their clients and one third of the providers reported dropping services that they used to provide.⁴⁶ With resources and providers stretched so thin, the accessibility of mental health services for uninsured and underinsured cancer patients is likely even further reduced than for patients with private insurance.

All cancer survivors deserve to have attention paid to their psychological and emotional well-being. While the effect of psychosocial interventions on cancer survival has been disputed,^{47,48,49} the effect of these support services on the mood, perception of pain, and overall quality of life of cancer survivors is undeniable.^{50,51,52}

Long-Term Survivorship

With the progress and breakthroughs that research has brought to cancer treatment, more people are surviving cancer and living longer. With that development comes a responsibility to ensure that cancer survivors receive continuous and long-term care. There are many long-term effects of cancer and treatment that are of great concern and need to be addressed, such as:

- What are the long-term effects of cancer treatments?
- Will my cancer return or will I be diagnosed with other cancers?
- How will I deal with the long-term medical and emotional side effects of cancer?
- How will my family cope over the long term?
- Who will help me through fertility issues specific to cancer survivorship?
- How will I learn about genetic risks among my children or siblings?
- Will I be able to go back to work? Will I need retraining?
- Will educators understand the emotional, physical, and cognitive needs of student cancer survivors?

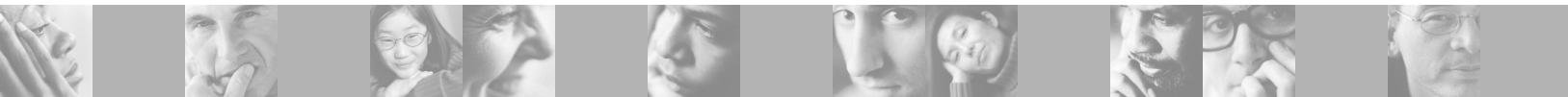
A survey conducted among cancer survivors at the M. D. Anderson Comprehensive Cancer Center at the University of Texas indicated that 34% of the participants felt that having cancer had affected their overall health.⁵³ However, long-term cancer survivorship is a relatively new area of study and little is known about adult survivors of cancer. There is a great need for further research into the effects of cancer and its treatment and the development of interventions to reduce these effects. In 1996, the National Cancer Institute established the Office of Cancer Survivorship to support and promote research that addresses the physical, psychological, social, and economic issues of pediatric and adult cancer survivors and their families.⁵⁴ Enhancing long-term follow-up and ensuring the continuum of care for cancer survivors is necessary to reduce premature mortality and diminished quality of life associated with cancer and its treatment. Establishing cancer survivorship clinics in Maryland, like the Life After Cancer Care program at the M. D. Anderson Comprehensive Cancer Center in Texas and the Living Well After Cancer program at the University of Pennsylvania Cancer Center, would greatly enhance access to long-term follow-up services and coordinated care for survivors.

Conclusion

More than 24,400 people will be diagnosed with cancer in Maryland in 2003.⁵⁵ Three out of four families will help care for a family member with cancer. Fortunately, the number of cancer survivors is growing daily, due to advances in cancer detection, early diagnosis, aggressive and effective treatments, enhanced rehabilitative and support interventions, and active screening and healthier lifestyles by survivors. It is imperative that we take our charge seriously to help ease the challenge of a cancer diagnosis among our citizens and improve the lives of cancer survivors.

The investigation of issues faced by cancer patients in Maryland has brought to light many areas of concern. We have a great opportunity now to learn from this investigation and to set in place strategies to better serve the citizens of this state. These strategies can in fact be utilized in communities all over the country.

The citizens of Maryland are fortunate to live in close proximity to many cancer centers, agencies, and research programs that are furthering the cause of improved cancer treatment and possible cancer cures. Because our state already has the infrastructure and human resources available, implementing the recommendations contained herein can be readily accomplished.



Patient Issues and Cancer Survivorship Goals, Objectives, and Strategies

Goal:

Enhance the quality of life for all cancer survivors in Maryland.

Target for Change

By 2008, establish a Patient Issues and Cancer Survivorship Advisory Board to continuously assess the needs of cancer survivors in Maryland and to make recommendations to address those needs.

Objective 1:

Enhance access to information and resources for Maryland cancer survivors, their friends, and families.

Strategies:

1. Establish and market a comprehensive cancer information clearinghouse in the form of a website plus a staffed, toll-free telephone number. This website should house all pertinent information relating to national, regional, and local resources for cancer survivors. Consider the Cancer Gateway of Texas⁵⁶ and other existing state cancer websites as models for the Maryland website.
2. Encourage oncologists to distribute copies of the National Cancer Institute publications "Facing Forward" and "Life After Cancer Treatment" to all patients.
3. Identify Patient Navigator tools and systems for use in Maryland to facilitate patient access to cancer information, screening, diagnosis, and treatment.
4. Develop and implement a multimedia public service campaign to empower the public to be informed, proactive consumers of health care and to ask their doctors about appropriate cancer prevention and screening.
5. Educate community leaders throughout Maryland about available cancer resources and involve community leaders in helping to raise public awareness of issues faced by cancer survivors.

**Objective 2:**

Reduce the financial burden on cancer survivors and their families.

Strategies:

1. Examine the cost of cancer services and develop a statewide financial aid system to help offset the expense of cancer diagnosis and treatment services.
2. Initiate a review of the Maryland Medicaid system with attention to cancer costs.
3. Provide tax credits for chronically ill citizens.
4. Establish a paid medical leave program based on the best practices of existing programs.
5. Modify existing or develop new policies to ensure that patients with managed care insurance may have lab work, scans, and tests performed (and covered by their carrier) at the centers where they are already being treated rather than being forced to travel to other facilities.
6. Develop user-friendly transportation assistance programs to help patients get to and from treatment and medical appointments, support groups, education sessions, and other support services. Coordinate with existing transportation services and consider incentives such as tax credits for companies donating transportation services for cancer patients.
7. Mandate insurance coverage for fertility benefits to cover fertility counseling, sperm banking, or egg harvesting and storage for those affected by cancer treatments or surgeries.
8. Develop methods to increase access to physical and occupational therapy services as well as mental health services for cancer survivors.
9. Develop employer-employee education programs to make the workplace comfortable for survivors as they deal with cancer.
10. Mandate that life insurance be portable when one leaves employment.
11. Expand and develop new educational efforts to make cancer survivors and their families aware of pharmaceutical assistance programs.
12. Expand insurance coverage for screening for cancer survivors, who are often at risk for secondary cancers and other physical problems.
13. Develop programs to make childcare, eldercare, homecare or respite care available while patients are undergoing treatment and follow-up.

Objective 3:

Ensure that all cancer survivors have access to psychosocial support services throughout all phases of their cancer experience.

Strategies:

1. Educate health care practitioners to be aware of, and sensitive to, the psychosocial needs of their patients. Educate providers about existing mental health services and other psychosocial support services for cancer survivors and the urgent need for increased numbers of timely referrals for mental health services.
2. Establish an annual conference sponsored by the Maryland Department of Health & Mental Hygiene, academic health centers, and Maryland professional organizations to address psychosocial issues of cancer survivors.



3. Expand continuing education offerings to provide training in oncology mental health for those both within and outside the oncology arena. Consider providing certification in this field on the state level to practitioners including nurses, licensed professional counselors, psychologists, psychiatrists, social workers, occupational and physical therapists, physicians, and other health care workers who complete a course and designated hours of practice in oncology mental health.
4. Implement curricula on the psychosocial issues related to cancer in all Maryland universities offering programs in the health and social work professions. Consider the current curriculum written by Margaret Wool, PhD, MSW, being taught at Brown University as a model.⁵⁷
5. Provide incentives for prospective students entering the mental health profession to specialize in oncology.
6. Design and launch a media campaign to educate the public about the psychosocial issues related to cancer and to raise awareness and knowledge of the support services available throughout the state.

Objective 4:

Address the needs of long-term cancer survivors in Maryland.

Strategies:

1. Encourage and provide funding for survivorship research.
2. Establish new and expand existing long-term survivorship clinics in Maryland for both childhood and adult cancer survivors. These clinics should be designed to follow survivors after treatment and to provide them with comprehensive care to address the unique needs of cancer survivors. The Living Well After Cancer program at the University of Pennsylvania Cancer Center and the Life After Cancer Care program at the M. D. Anderson Comprehensive Cancer Center in Texas may provide models for such clinics.
3. Educate oncologists and other health care providers about long-term survivorship issues. Providers should be encouraged to explain the long-term effects of the different treatment options available and help their patients make treatment decisions with regard to these long-term effects.
4. Educate oncologists about the need to refer their patients to neurologists, cardiologists, physical therapists, or other specialists as necessary for the management of long-term side effects.
5. Identify or create new programs to address occupational issues of cancer survivors such as job retraining and workplace reintegration.
6. Increase awareness among educators about the specific physical, emotional, and cognitive needs of student cancer survivors, and of the emotional needs of the family members of cancer survivors.

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CHAPTER 5

TOBACCO-USE PREVENTION AND CESSATION AND LUNG CANCER

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TOBACCO-USE PREVENTION, CESSATION, AND LUNG CANCER

Tobacco-use prevention and cessation are central to comprehensive cancer control in Maryland. However, the full impact of tobacco use reaches far beyond its impact on cancer. Tobacco use causes the premature death from all tobacco-related diseases (including cancer and heart and lung disease) of more adults each year in Maryland than all the lives lost to terrorism on September 11, 2001. The annual death toll from tobacco-related disease in Maryland exceeds the state's combined combat death toll from World War II and the Korean and Vietnam Wars (Figure 5.1).¹

Currently, tobacco use is estimated to cost the Maryland economy in excess of \$3 billion annually, including \$1.5 billion in added health care costs. The cost of providing additional tobacco-related health care services to Maryland residents adds an estimated \$552 to the average Maryland household's combined state and federal income tax bill.^{2,3}

The human and economic toll that tobacco use exacts from Maryland residents will only decline when fewer

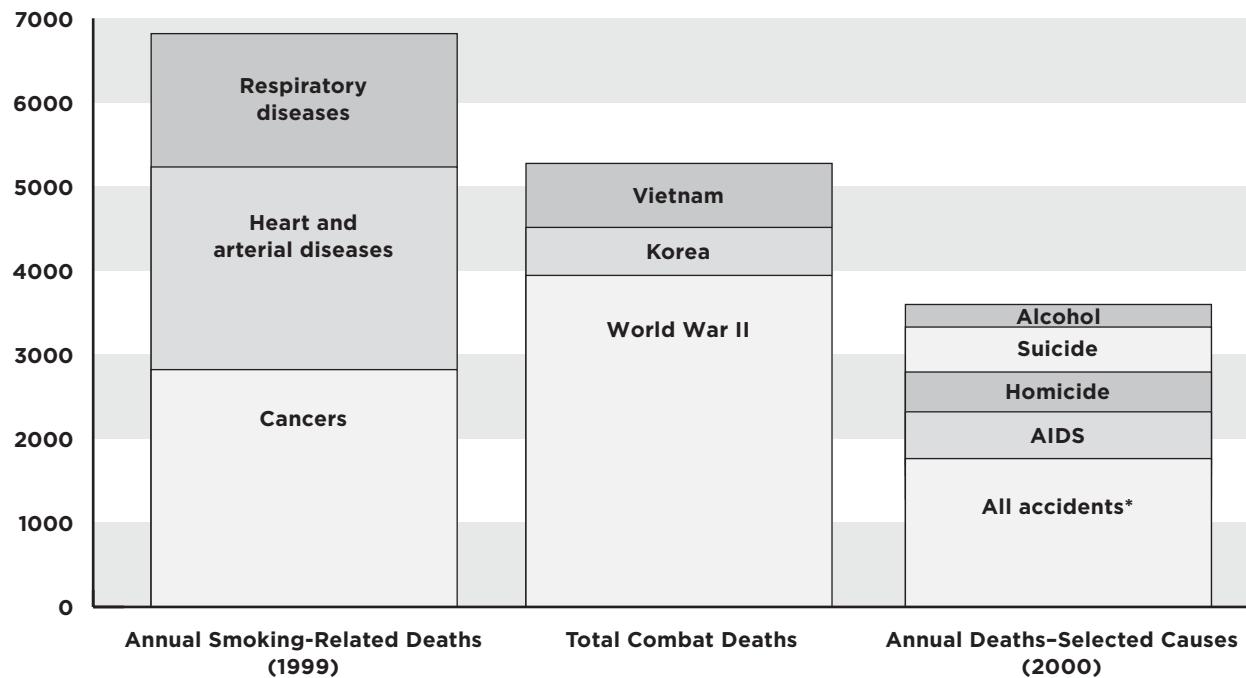
Marylanders choose to use tobacco products. From both a health and economic perspective, it is imperative that Maryland continues to take steps to reduce tobacco use.

Burden of Tobacco-Related Disease

Tobacco use has been found to be a cause of cancer, heart disease, and respiratory disease. The Centers for Disease Control and Prevention (CDC), using data from 1999, conservatively estimates that at least 6,800 adult Maryland residents die prematurely *each* year as a result of cigarette smoking ("smoking"),⁴ 42% of which are due to cancer. The number of people who die prematurely as a result of the use of tobacco products other than cigarettes, such as chewing tobacco, pipes, and cigars, are not included in this estimate. Likewise, premature deaths resulting from exposure to second-hand smoke are not included in this estimate. More Marylanders are dying prematurely each year as a result of smoking cigarettes than are dying from the combined effects of alcohol, drugs, homicide, suicide, AIDS, and accidents (Figure 5.1).⁵ In addition, 18 Maryland infants are estimated to die each year as a result of their mothers smoking during pregnancy.

Smoking and tobacco use are associated with a number of different cancer types and sites.⁶ Table 5.1 shows the proportion of cancers at various sites that are attributable to smoking in Maryland, by sex and age. For example, 89% of deaths from cancer of the lung, bronchus, or trachea in men 35–64 years of age are estimated to be attributable to smoking. Given the number of cancers of these sites reported in Maryland

Figure 5.1
Maryland Deaths: A Comparison of Selected Causes



Compiled by the CRF Tobacco-Use Prevention and Cessation Program.

*All accidents refers to transportation and non-transportation accidents.

Sources: Smoking-related deaths: CDC SAMMEC <http://apps.nccd.cdc.gov/sammec/>.

Combat deaths: National Archives <http://www.archives.gov>.

Selected causes: Maryland Vital Statistics Administration <http://www.mdpublichealth.org/vsa>.

in 1999, it is estimated that 2,871 deaths in people 35 years and older from these cancers were attributable to tobacco use, of which 2,278 (79%) were cancer of the lung, bronchus, or trachea (Table 5.2).

Lung Cancer

Lung cancer is the leading cause of cancer deaths in both men and women in Maryland, accounting for 28.6% of all cancer deaths between 1995 and 1999 (Figure 1.5, Chapter 1). Figures 1.6 and 1.7, also in Chapter 1, show lung cancer deaths rising rapidly to become the major cause of cancer mortality among men in the nation, and rising thereafter among women. The death rate peaked for men in 1990; the rate of increase in women slowed in the 1990s.

Lung cancer, or primary cancer of the lung and bronchus, is comprised of two major categories: small cell carcinoma (accounting for 20%–30% of lung cancer) and non-small cell carcinomas. Non-small cell lung cancers include squamous cell carcinoma, adenocarcinoma, and large cell carcinoma (accounting for

30%–40%, 40%–50%, and 10%–15% of all lung cancers, respectively).⁷ Each type has different patterns of spread, treatment, and prognosis. Lung cancer typically spreads within the chest and to lymph nodes of the chest, and also to distant sites, predominantly the brain, bone, liver, adrenal gland, and the other lung.

According to Maryland Cancer Registry staging, lung cancer is considered “localized” if it consists of single or multiple tumors confined to one lung and/or one main stem bronchus. “Regional” tumors are either locally invasive or have spread to lymph nodes within the chest. “Distant” lung cancers have spread more widely in the chest or to distant lymph nodes or other organs.⁸ From 1992 to 1999, the overall five-year survival rate for lung cancer was 14.9% (48.5% for local stage, 21.7% for regional stage, and 2.5% for distant staged tumors).⁹ The survival rate for whites exceeds that of blacks (15.1% vs. 12.4%). Five-year survival rates are higher for non-small cell cancer than for small cell cancer of the lung (all stages 16.3% vs. 6.4%; SEER, 1992–1998).¹⁰

Table 5.1
Proportion of Cancer Deaths Attributable to Smoking by Site in Maryland, 1999
(Smoking Attributable Fractions)

Cancer Site	MALES		FEMALES	
	Age 35-64*	Age 65+	Age 35-64*	Age 65+
Lip, oral cavity, pharynx	76%	68%	53%	45%
Esophagus	71%	70%	64%	55%
Pancreas	26%	16%	28%	23%
Larynx	83%	80%	77%	72%
Lung, bronchus, or trachea	89%	86%	76%	70%
Cervix uteri	-	-	13%	9%
Urinary bladder	47%	43%	31%	29%
Kidney and renal pelvis	39%	35%	6%	4%

*The number of deaths among persons less than 35 years of age was too small to attain statistical significance.
Source: SAMMEC.

Table 5.2
Total Cancer Deaths by Select Site and Age Group in Maryland, 1999

Site	Total deaths, all ages	Deaths among those age 35+	Deaths among those age 35+ estimated to be attributable to smoking
Oral Cavity and pharynx	144	140	96
Esophagus	237	237	162
Pancreas	557	557	122
Larynx	90	90	74
Lung, bronchus, and trachea*	2,842	2,837	2,278
Cervix uteri	77	74	9
Urinary bladder	228	226	90
Kidney and renal pelvis	171	169	40
Total	4,346	4,330	2,871

*The 2,842 deaths include five or fewer deaths from cancer of the trachea in addition to the lung and bronchus cancer deaths (the data-use policy of MCR/DHMH does not permit specification of numbers of cases less than or equal to five cases).
Source: Maryland Cancer Registry; SAMMEC.

Risk Factors for Lung Cancer

Smoking

Conceptually, lung cancer can be described as a multi-step developmental process occurring over the entire lung surface where multiple independent cancerous lesions may be developing.¹¹ Tobacco smoke contains carcinogens including benzene, nitrosamines, vinyl chloride, arsenic, and polynuclear aromatic hydrocarbons (PAHs), including the classic carcinogen benzo[a]pyrene (BaP), and the nicotine-derived tobacco-specific nitrosamine, 4-(methylnitrosamino)-1-(3-pyridyl)-1-butanone (NNK), in addition to toxins and irritants (such as carbon monoxide, nicotine, hydrogen cyanide, and ammonia).^{12,13} Carcinogens cause genetic damage that leads to lung cancer. When a person inhales tobacco smoke, carcinogens come in direct contact with surfaces of the mouth, trachea, and lung, and may be also absorbed into the blood and circulated through the body. Additionally, saliva that contains carcinogens from smoke gets swallowed and carcinogens come in contact with the esophagus, stomach, and intestines. People who smoke are likely to have multiple premalignant lesions within the lungs.¹⁴

Tobacco smoking is estimated to cause 90% of lung cancer in men and 78% of lung cancer in women; cigar and pipe smoking have also been associated with increased lung cancer risk.¹⁵ The risk of lung cancer and smoking is dose-dependent, i.e., dependent on the duration of smoking, the number of cigarettes smoked per day and the inhaling pattern. For example, heavy smokers (more than 40 cigarettes per day for several years) have a 20 times greater risk of getting lung cancer than non-smokers.¹⁶ Eighty percent of lung cancers occur in smokers. A 30% to 50% reduction in lung cancer mortality risk has been noted after 10 years of cessation.¹⁷

The risk of lung cancer from cigar smoking is less than from cigarette smoking; however, lung cancer risk from moderately inhaling smoke from five cigars a day is comparable to the risk from smoking up to one pack of cigarettes a day.¹⁸ The prevalence of tobacco use in Maryland adults and youth is described in detail later in the chapter.

Secondhand (or environmental) tobacco smoke

Secondhand tobacco smoke contains the same chemicals but in lower concentrations (1%–10% depending on the chemical) than those to which the smoker is exposed.¹⁹ Secondhand smoke has been found to be a

risk factor among nonsmokers, increasing the risk of tobacco-related cancer by 20% (a relative risk of 1.2).²⁰

Other Exposures

Radiation (such as uranium), occupational exposure to nickel, chromates, coal, mustard gas, arsenic, beryllium, and iron, and occupational exposures (among newspaper workers, African gold miners, and halo-ether workers, for example) increase the risk of lung cancer.²¹ Asbestos causes lung cancer and mesothelioma (cancer of the pleura or surface membrane of the lung). Exposure to asbestos is synergistic with smoking exposure in increasing an exposed person's risk of lung cancer, but not of mesothelioma.²² In miners, radon (independently and increasingly with smoking) is an established lung cancer risk factor. Epidemiologic data on radon in the home as a risk factor for lung cancer have been preliminary and limited. However, the lifetime relative risk for residing in a home at the Environmental Protection Agency action level of four picocuries per liter has been estimated at about 1.4 for smokers and 2.0 for nonsmokers.²³

Age

In 1999, less than 1% of lung cancer cases in Maryland were diagnosed in people younger than 30 years of age. This rate increases markedly with each decade after age 30. Among smokers, however, increasing age is also correlated with an increasing exposure to smoke.

Prior Lung Cancer

The lifetime risk of second primary lung cancers in people with early stage lung cancer is 20%–30%.²⁴

Burden of Lung Cancer in Maryland

Lung cancer is the leading cause of cancer deaths in both men and women in Maryland, accounting for 28.6% of all cancer deaths between 1994 and 1998 (see Figure 1.5, Chapter 1). Lung cancer is the third leading cause of new cancer cases in Maryland after prostate and breast cancer. (See Figure 1.5 in Chapter 1.) In 1999, 3,447 people in Maryland were diagnosed with lung cancer (71.6/100,000 of the age-adjusted rate) and 2,841 people died of lung cancer (59.4/100,000; significantly higher than the U.S. rate of 56.0/100,000). Table 5.3.

Maryland's death rate from lung cancer in 1999 was 18th highest among the states and the District of Columbia. Figure 5.2 shows the trend in the cases and deaths from 1995–1999. During this period, Maryland had an annual 3.3% decrease in incidence and a 2.2%

decrease in mortality rate.²⁵ Over this same period, the incidence among white and black women has remained essentially stable while the rate among men, especially black men, has decreased markedly (from 144.9/100,000 to 105.2/100,000; Figure 5.3). Overall, women have just over half the rate of lung cancer as men. Mortality trends have similarly shown the greatest declines among black men; however, the mortality rate of black men remains over twice the rate in white or black women (103.3/100,000 compared to 45/100,000). Figure 5.4.

Incidence and mortality rates vary markedly by age, and Maryland's incidence rates exceed the U.S. rates at all ages (Figure 5.5). Rates peak among men at ages 75–84 and among women at ages 70–79 (Figure 5.6); black men have the highest rates at all ages. Figure 5.7 shows the lung cancer mortality rates from 1995–1999 in Maryland's 24 jurisdictions. Montgomery County had a rate statistically significantly lower than the U.S. rate while 12 jurisdictions in the eastern half of the state had rates that were statistically significantly higher than the U.S. rate.

Table 5.3
Lung Cancer Incidence and Mortality by Sex and Race
in Maryland and the United States, 1999

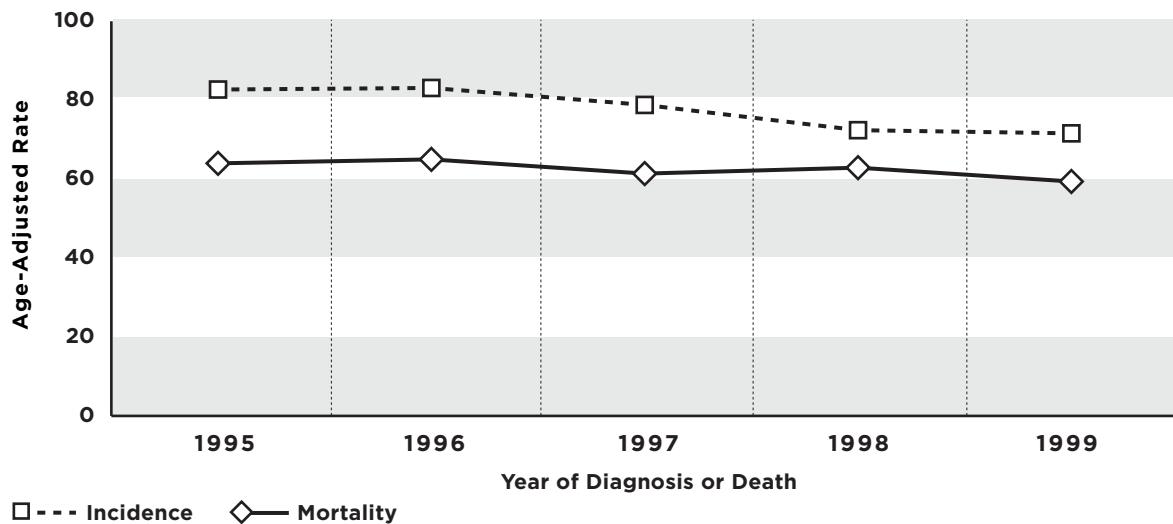
Incidence 1999	Total	Males	Females	Whites	Blacks	Other
New Cases (#)	3447	1904	1542	2650	736	53
Incidence Rate	71.6	92.4	56.8	71.5	75.8	39.3
U.S. SEER Rate	63.5	81.1	50.7	63.5	81.4	NA
Mortality 1999	Total	Males	Females	Whites	Blacks	Other
MD Deaths (#)	2841	1624	1217	2182	636	23
MD Mortality Rate	59.4	81.2	44.4	58.8	68.3	**
U.S. Mortality Rate	56.0	77.2	40.7	55.9	65.5	NA

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

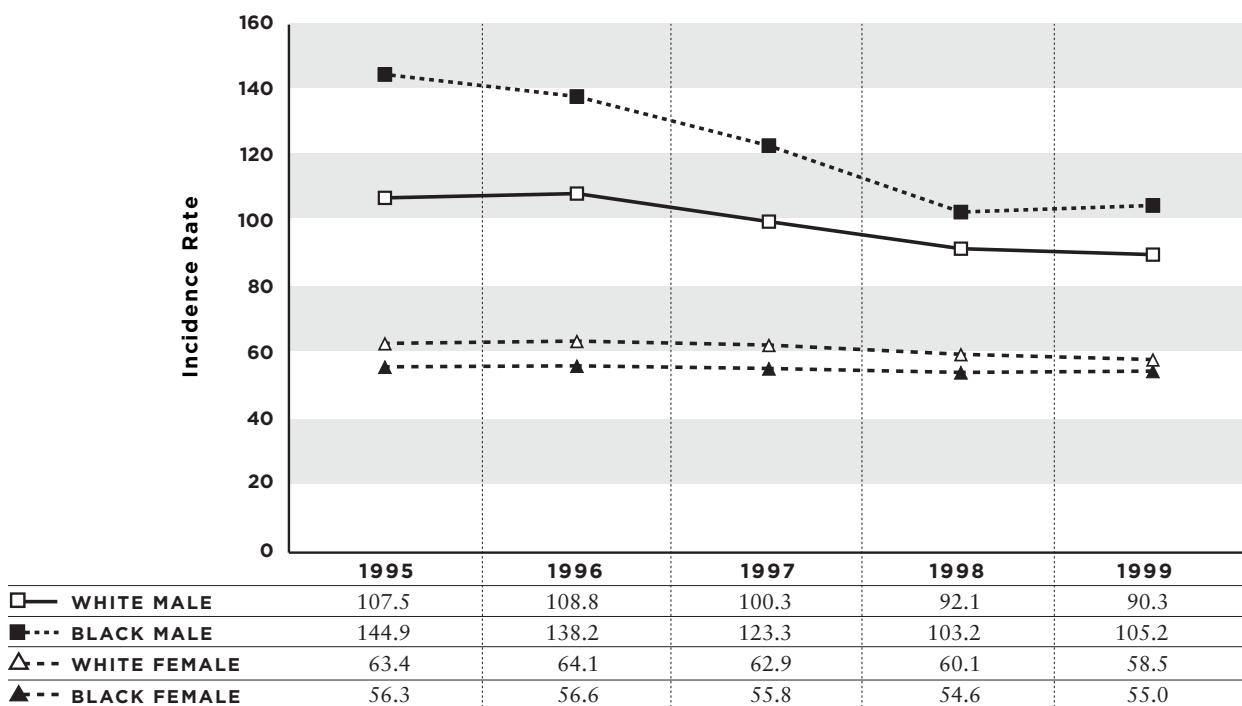
**Rates based on cells with 25 or fewer non-zero cases are not presented per DHMH/MCR Data-Use Policy.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

Figure 5.2
Lung Cancer Incidence and Mortality by Year of Diagnosis and Death
in Maryland, 1995–1999

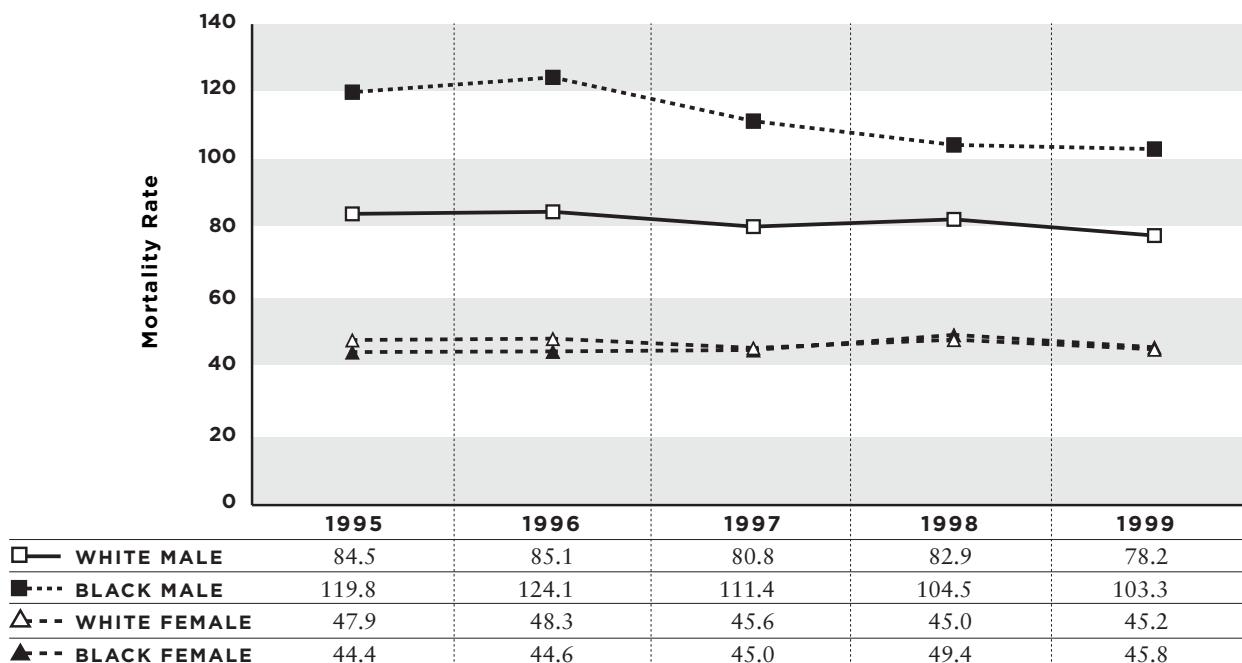


Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995–1999; Maryland Division of Health Statistics, 1995–1999.

Figure 5.3**Lung Cancer Incidence Rates by Race and Sex in Maryland, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

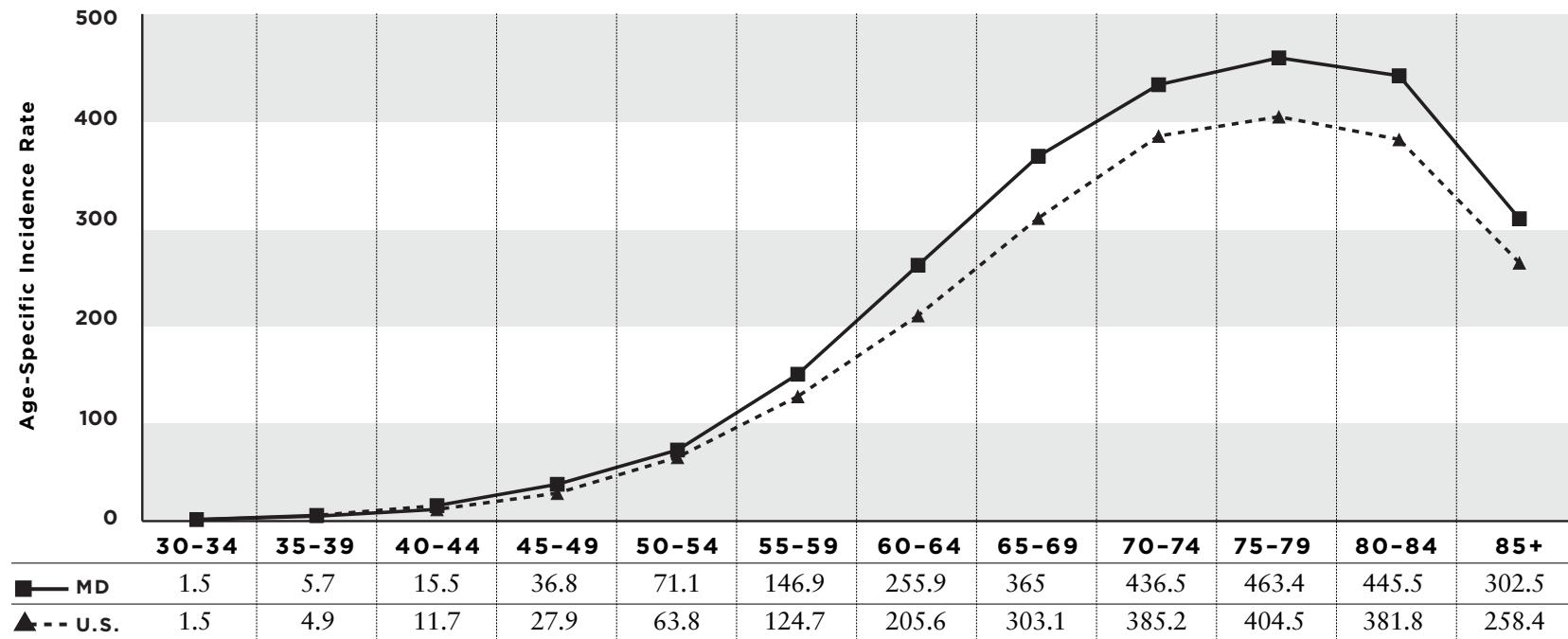
Source: Maryland Cancer Registry, 1995-1999.

Figure 5.4**Lung Cancer Mortality Rates by Race and Sex in Maryland, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Division of Health Statistics, 1995-1999.

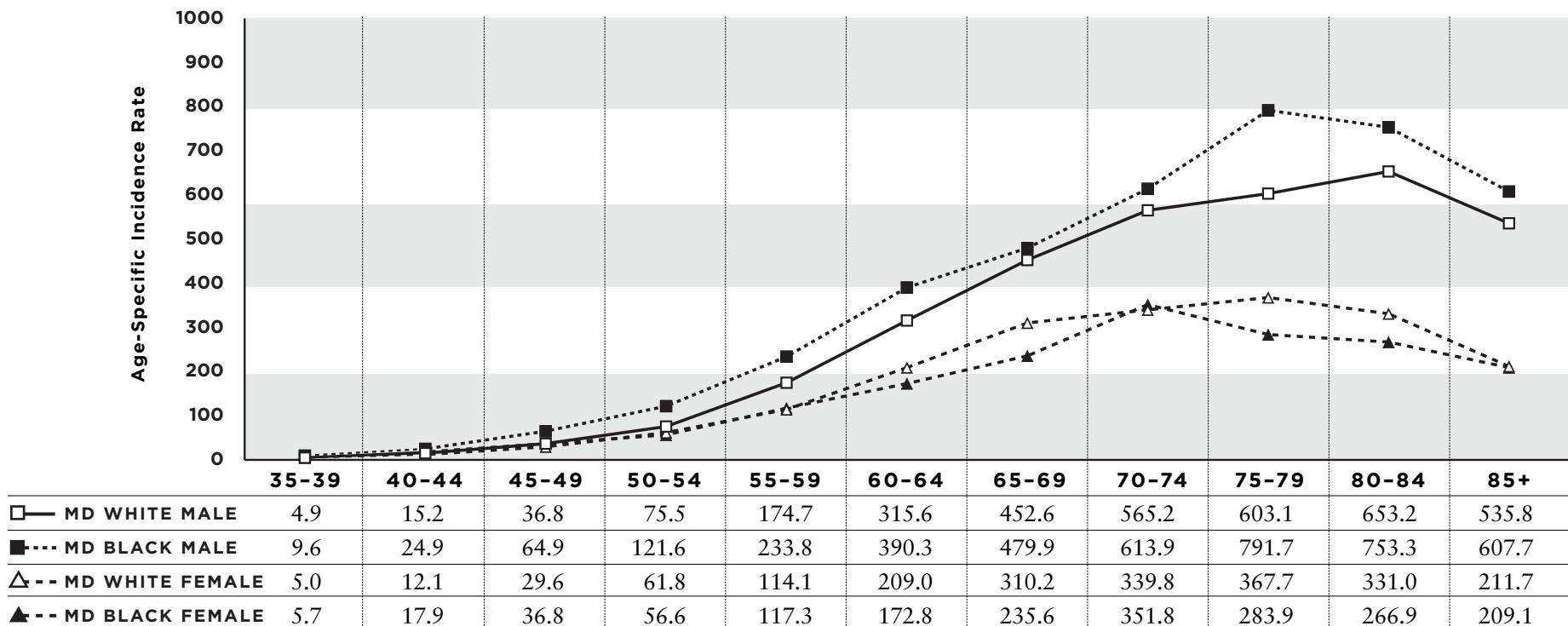
Figure 5.5
Lung Cancer Age-Specific Incidence Rates in Maryland and the United States, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 5.6
Lung Cancer Age-Specific Incidence Rates by Race and Sex in Maryland, 1995-1999

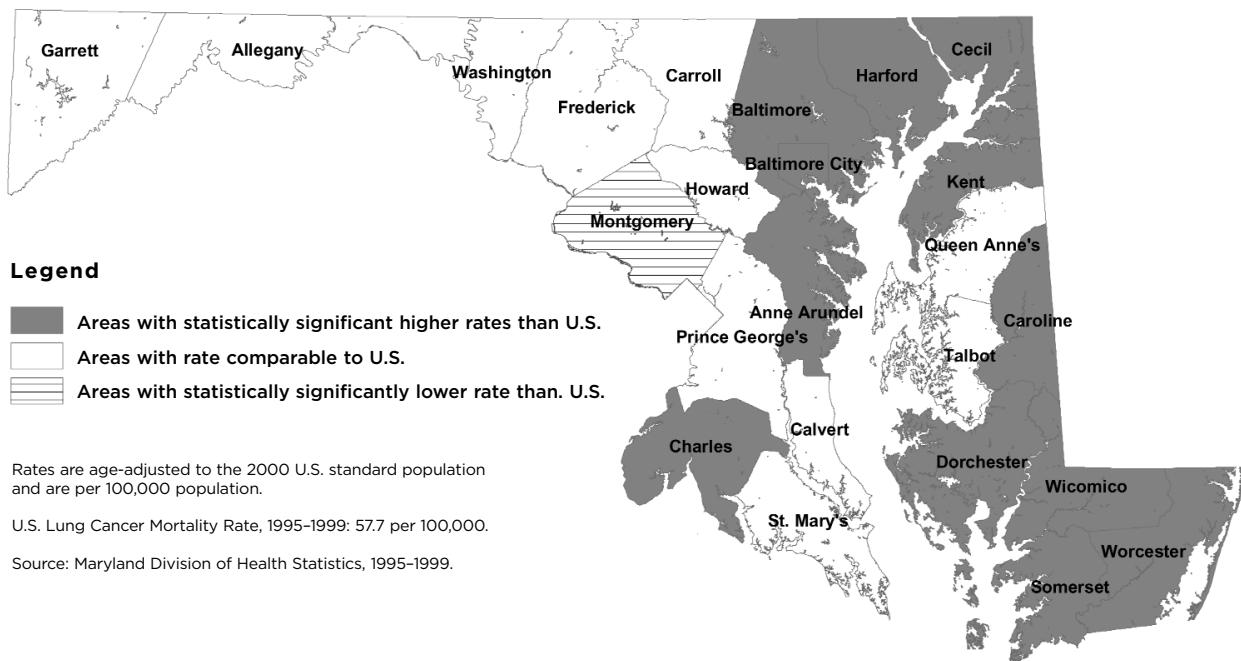


Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1995-1999.

Figure 5.7

**Maryland Lung Cancer Mortality Rates by Geographical Area:
A Comparison to United States Rates, 1995–1999**



In 1999, 21% of Maryland lung cancer cases were reported as local stage at the time of diagnosis, 26.7% were regional stage, 35.8% were distant stage, and 16.6% were unstaged. Both blacks and whites were less likely to have distant stage disease at the time of diagnosis and more likely to have localized or regional disease compared to U.S. SEER rates (Figure 5.8). However, among Marylanders with lung cancer, blacks are more likely to have their lung cancer diagnosed in the regional or distant stage (Figure 5.9). Survival data are not available for Maryland cases.

Disparities

- At all ages, black men have the highest rate of new cases of, and deaths from, lung cancer.
- Black men had a sharper decline in the incidence of lung cancer between 1995–1999 than white men or black and white women, but their rate of lung cancer remains the highest of these groups.
- Black men and women were more likely to be diagnosed with distant-stage lung cancer in Maryland than their white counterparts between 1992 and 1997.

Primary Prevention of Lung Cancer

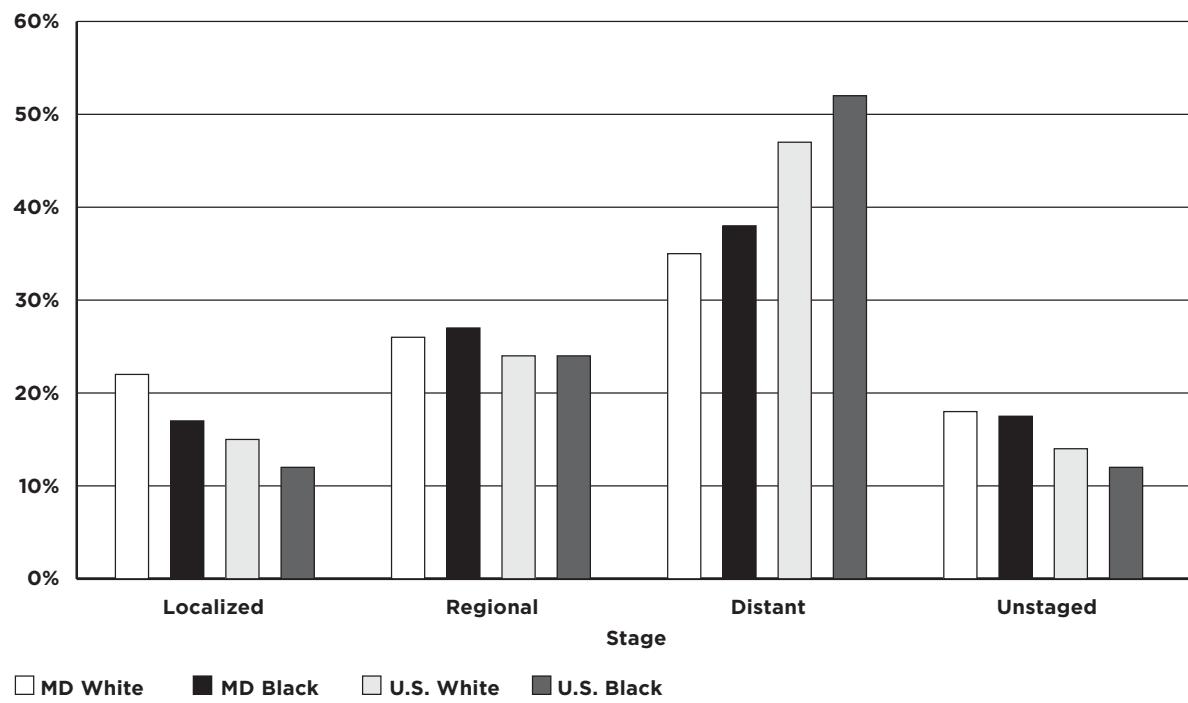
The majority of lung cancers could be prevented through “primary prevention,” that is, prevention and cessation of tobacco use. In addition, primary prevention of lung cancer includes policies that reduce exposure to secondhand smoke. Discussion of interventions that decrease exposures to other chemicals that are associated with lung cancer risk (e.g., radon, asbestos, and occupational exposures) is beyond the scope of this chapter.

Chemoprevention and Reversal of Premalignancy

Investigation of chemopreventive agents and agents that can reverse premalignant changes in the lungs of smokers is under research investigation at this time.²⁶ Because a high level of consumption of fruits and vegetables has been associated with lower risk of lung cancer, even when controlling for smoking,²⁷ trials of supplementation have been conducted. Two randomized, controlled clinical trials have studied beta-carotene supplements for chemoprevention of lung cancer. They have shown that pharmacological doses (20 mg/day or greater) of beta-carotene supplementation may, in fact, increase lung cancer incidence and mortality among high-intensity smokers (one or more packs per day).²⁸

Figure 5.8

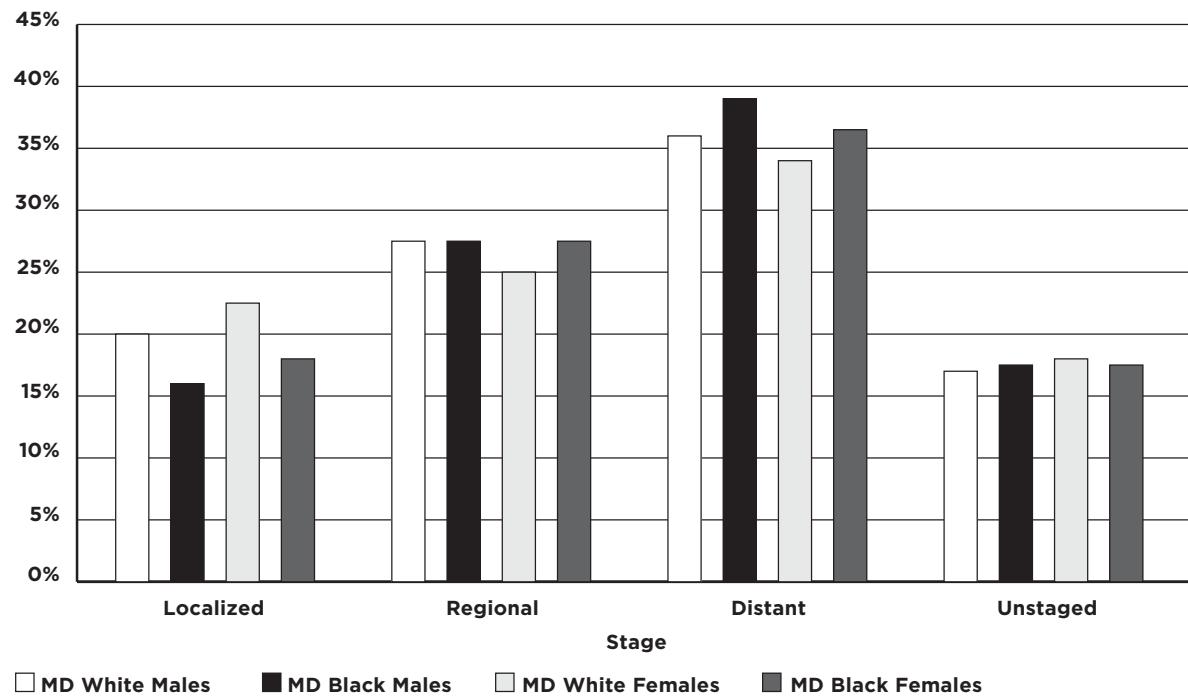
Lung Cancer Distribution of Stage at Diagnosis by Race in Maryland and the United States, 1992-1997



Source: Maryland Cancer Registry, 1992-1997; SEER, National Cancer Institute, 1992-1997.

Figure 5.9

Lung Cancer Distribution of Stage at Diagnosis by Race and Sex in Maryland, 1992-1997



Source: Maryland Cancer Registry, 1992-1997.

Screening for Lung Cancer

Current evidence does not support lung cancer screening by chest X-ray or sputum cytology.^{29,30} Randomized trials have shown that these tests do not lead to a reduction in lung cancer mortality. Low dose spiral computerized tomography (CT) of the chest or “spiral CT” is available now commercially, although it has not been shown to decrease mortality from lung cancer. It is currently undergoing comparison to chest X-ray in the National Lung Cancer Screening Trial to determine whether it will lower mortality.³¹ Screening tests for lung cancer are not recommended by the American Cancer Society, the U.S. Preventive Services Task Force, the National Cancer Institute, or the American College of Radiology; all strongly endorse smoking cessation for prevention.³²

Other Tobacco-Related Cancers

In addition to lung cancer, there are a number of other cancers that can be attributed to tobacco use (Table 5.1).³³ Table 5.2 shows the total number of these cancer deaths reported in Maryland in 1999, the number who were 35 years of age or older at the time of death, and the number that are estimated to be attributable to tobacco use. There were a total of 4,330 deaths in Marylanders 35 or over due to these cancers, 2,871 of which were estimated to be attributable to smoking. A portion of cancers of the esophagus, pancreas, larynx, bladder, and kidney are attributable to smoking (Table 5.1), but at this time primary prevention through tobacco-use prevention and cessation, and not screening, is recommended to reduce the rates of these cancers.

Tobacco Use by Maryland Adults

Maryland's first comprehensive study of tobacco use by adults in the state occurred in the fall of 2000 when the Maryland Adult Tobacco Survey (MATS-00) was conducted. For the first time, specific estimates of adult tobacco use by county became available to policy makers and program personnel. Unless otherwise stated, the statistics in this section are from the 2000 MATS.³⁴

Any Tobacco Use

Tobacco is used in one form or another by 21.8% ($\pm 0.95\%$) of Maryland adults. Considerable variation in the prevalence of tobacco use was noted, ranging from a low of 14.3% ($\pm 2.45\%$) of adults in Montgomery County, to a high of 31.4% ($\pm 3.45\%$) of adults in Baltimore City. Over 842,000 Maryland adults use some

form of tobacco product.

Cigarette Smoking

Cigarettes are the most commonly used tobacco product, with 17.5% ($\pm 0.85\%$) of Maryland adults reporting they were current cigarette smokers. The percent of adults who are current smokers ranges from a low of 9.3% ($\pm 2.00\%$) in Montgomery County to a high of 28.3% ($\pm 3.40\%$) in Baltimore City. The majority of adults report they started smoking while still under the age of 18.

Other Tobacco Products

In addition to cigarettes, Maryland adults reported using smokeless tobacco (1.1% $\pm 0.20\%$) and other tobacco products (6.8%) such as pipes, cigars, bidis, and kreteks.

Tobacco and Race/Ethnicity

In Maryland, there does not appear to be any statistically significant difference in the use of tobacco products between African Americans, Hispanics, or whites (Figure 5.10). Although the data suggest that Asian Americans use tobacco at significantly lower rates than do the other racial/ethnic groups, this may be due to the fact that relatively few Asian Americans participated in that survey.

Tobacco and Education /Income

Smoking is related to socioeconomic status. Figures 5.11 and 5.12 show smoking rates among adults in Maryland by highest educational attainment and by self-reported annual income. Those who did not complete high school are almost four times as likely to smoke as Maryland adults who are college graduates (34.3% vs. 8.9%). Those who reported that their income was less than \$25,000 were twice as likely to smoke as those who reported income of \$50,000 and higher (27.5% vs. 13.5%).

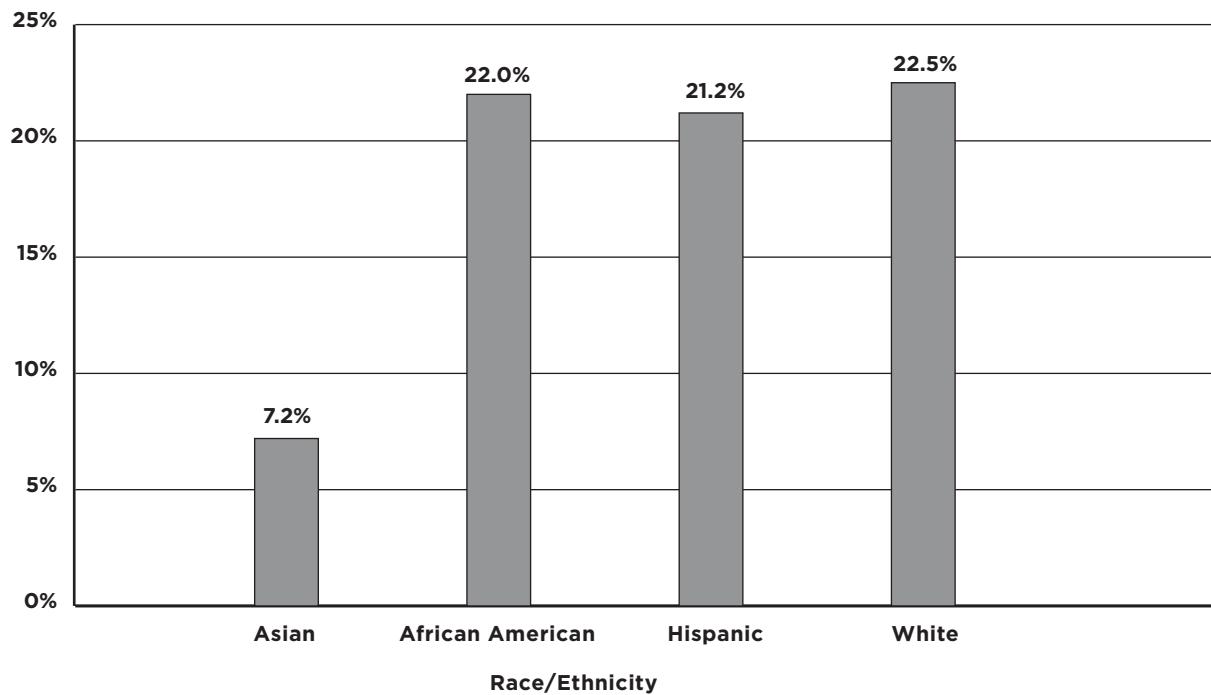
Tobacco and Gender

In Maryland, 27.7% of adult males report using some form of tobacco product, and 19.5% report smoking cigarettes. In comparison, only 16.5% of females report using tobacco products, with 15.7% reporting cigarette smoking.

Tobacco Use by Maryland Youth

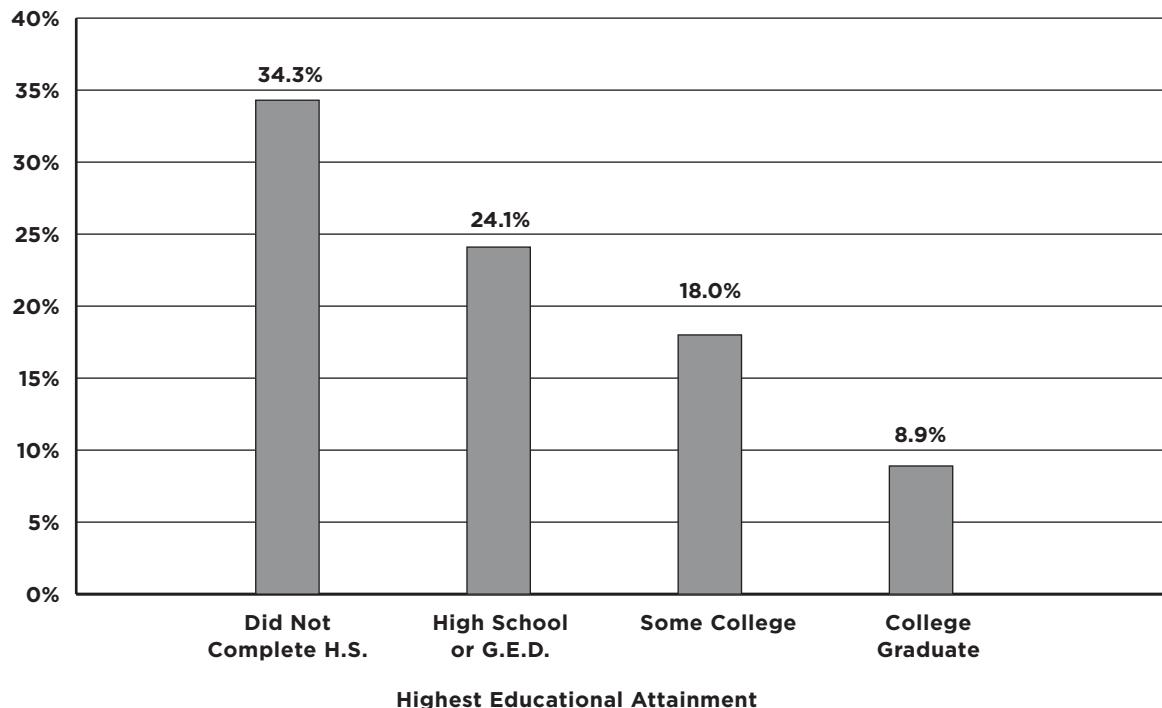
Maryland's first comprehensive study of tobacco use by youth in the state occurred in the fall of 2000 when the

Figure 5.10
Maryland Adults Who Smoked Cigarettes in the Past 30 Days by Race/Ethnicity, 2000



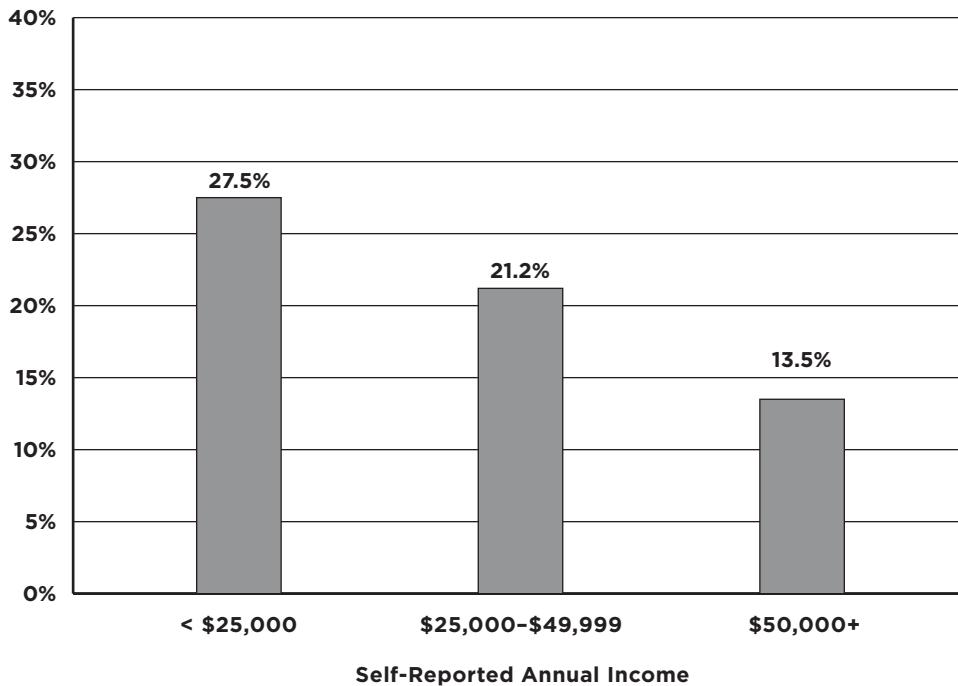
Source: Maryland Adult Tobacco Survey, 2000.

Figure 5.11
**Maryland Adults Who Smoked Cigarettes in the Past 30 Days
by Highest Education Attainment, 2000**



Source: Maryland Adult Tobacco Survey, 2000.

Figure 5.12
Maryland Adults Who Smoked Cigarettes in the Past 30 Days
by Self-Reported Annual Income



Source: Maryland Adult Tobacco Survey, 2000.

Maryland Youth Tobacco Survey (MYTS-00) was conducted. For the first time, specific estimates of youth tobacco use by county became available to policy makers and program personnel. Unless otherwise stated, the statistics in this section are from the 2000 MYTS.³⁵

Any Tobacco Use

An estimated 21.4% ($\pm 1.25\%$) of underage Maryland youth attending public middle and high schools use some form of tobacco product. The prevalence of underage tobacco use varies considerably among communities, from a low of 16.6% ($\pm 4.3\%$) in Montgomery County to a high of 33.9% ($\pm 4.25\%$) in Somerset County. Over 87,000 underage Maryland youth use some form of tobacco product.

Cigarette Smoking

Cigarettes are the single most popular tobacco product with Maryland youth. Overall, 16.3% ($\pm 1.1\%$) of Maryland youth attending public middle and high schools reported they had used cigarettes in the past 30 days. Like the adult population, the prevalence of cigarette smoking among middle and high school youth varies considerably across the state, from a low of

10.6% ($\pm 2.55\%$) in Prince George's County to a high of 29.2% ($\pm 4.65\%$) in Somerset County.

Smoking by Grade

Smoking rates increase linearly by grade (Figure 5.13) from 2.7% among 6th graders to an overall cigarette smoking prevalence among 12th graders in Maryland of 30.8%. The highest county-specific rate of 49.5% was among 12th graders in Somerset County.

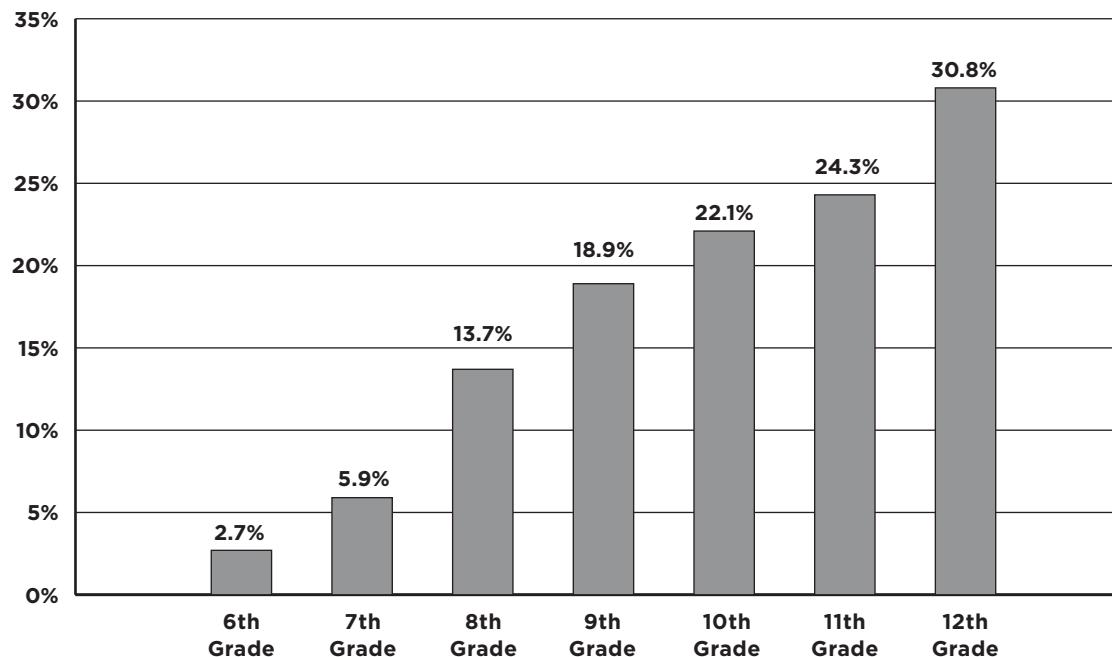
Other Tobacco Products

Maryland youth, like adults, also use a variety of tobacco products other than cigarettes. The rate for the use of smokeless tobaccos, such as chewing tobacco, snuff, or dip, is a relatively low 1.1% statewide. However, use can be as high as 6% overall, and was 15.1% among 12th graders in Garrett County.

Tobacco and Race/Ethnicity

Tobacco use among Asian-American youth is 19.7%, among African-American youth it is 18.6%, among Hispanic youth it is 23.8%, and among white youth it is 23.8%.

Figure 5.13
Current Cigarette Smoking by Maryland Youth



Source: Maryland Adult Tobacco Survey, 2000.

Tobacco and Gender

There does not appear to be a significant difference in tobacco use by sex among youth; an estimated 23.6% of males use tobacco products, compared to 20.3% of females.

Exposure to Secondhand Smoke

Exposure to secondhand smoke subjects individuals to a substance which poses a significant health hazard. The overwhelming scientific consensus is that secondhand smoke causes lung cancer in non-smokers, is responsible for lung infections among adults and children, and aggravates, if not causes, a variety of respiratory conditions in children, including asthma.³⁶

Since 1993, Maryland has restricted smoking in the workplace with a few notable exceptions. Smoking is still permitted without any requirement for a separate enclosed space or ventilation in most establishments where alcohol is served. Unless otherwise stated, the statistics in this section are from the MATS and MYTS.

Youth

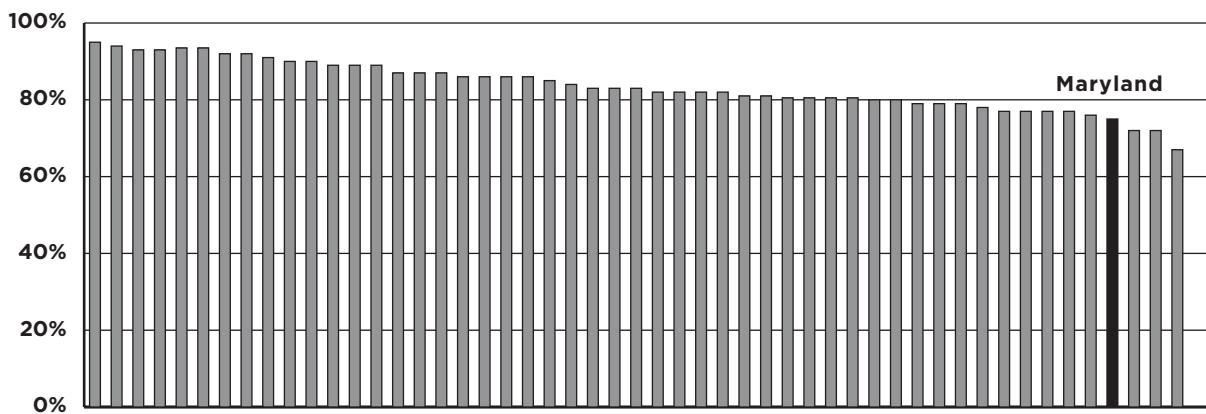
Overwhelming numbers of Maryland youth believe that being exposed to the smoke from other people's cigarettes is harmful to their health (almost 87% of middle school youth and over 88% of high school youth). Notwithstanding this belief, a significant proportion report being exposed to secondhand smoke at home and in the community. When asked if they had recently been in a room or a car while someone was smoking, over 50% of middle school youth and 68% of high school youth reported that they had.

Although only 17.5% of Maryland adults report that they smoke cigarettes, 42% of Maryland middle and high school youth report that they live with adult smokers. This creates a significant potential for exposure to secondhand smoke. Additionally, it creates a false impression among youth that the prevalence of cigarette smoking in the adult population is much higher than the data indicates.

Adults

In excess of 88% of Maryland adults believe that exposure to secondhand smoke can be harmful to their

Figure 5.14
Retailer Compliance Rates with Restriction of Tobacco Sales to Minors by State for Federal Fiscal Year 2000



Source: Data Source: Center for Substance Abuse Prevention; State Synar Non-Compliance Rates, FFY 1997–FFY 2002.
<http://www.prevention.samhsa.gov/tobacco/OIsynartable.asp>.

health. Almost 92% believe that such exposure can be harmful to the health of children. A significant percentage of these adults take these concerns to heart, with 80% reporting that their homes had been smoke-free during the previous week.

Unlike a home, where rules about smoking are totally under the control of a person or family, most Maryland adults must rely on employers' smoking policies, governmental restrictions, and compliance to prevent being exposed to secondhand smoke. Overall, 82% of adults report that smoking is prohibited at their worksite and almost 76% of working adults report that no smoking occurs indoors at their workplace.

Maryland's existing restrictions on smoking in the workplace provide the greatest protection to those with the highest incomes and education. Over 84% of working adults with a college degree report that smoking does not occur in their workplace as compared to the same reporting by 63% of those who had not graduated high school. Similarly, over 81% of those earning \$50,000 a year or more report that no smoking occurs in their workplace as compared to the 65% of those earning less than \$25,000 a year.

Youth Access

Every state, including Maryland, prohibits the sale of tobacco products to youth who are under 18 years of age (even older in some jurisdictions). Tobacco retailers assume a responsibility to the community they serve to

comply with these community standards regarding tobacco use. The obligation to sell tobacco products responsibly is not a new one. Maryland's prohibition on the sale of tobacco products to minors has been in existence since the 1800s. Given the statute prohibiting the sale of tobacco products to minors and its long history, all Maryland retailers know, or should know, that they cannot legally sell tobacco to persons under the age of 18.

What is new, however, is the evidence and consensus on the dangers of tobacco use, the addictive nature of tobacco products, evidence of a history of marketing that targets underage youth, and a realization of the critical importance of reducing underage initiation of tobacco use.

A Changing Retail Culture

Maryland and most other states began random inspections of tobacco retailers during Federal Fiscal Year 1997 (FFY 97) to determine the degree of retailer compliance with the obligation for responsible retailing. These "SYNAR" inspections are conducted annually under federal mandate.

As a condition to receiving its Substance Abuse Federal Block Grant, Maryland is required by federal law to establish that (1) it has laws in place prohibiting the sale and distribution of tobacco products to persons under 18 and (2) that it is enforcing those laws effectively. States are to achieve a compliance rate of at least 80 percent by FY 2003. This requirement is commonly referred to as the

“SYNAR Amendment,” named after Oklahoma’s former U.S. Congressman Mike Synar, who sponsored the federal legislation.

When these inspections began in 1997, Louisiana reported the lowest rate of retailer compliance (27.3%). In Maryland, only 54.3% of retailers were compliant that year. Only four states had compliance rates above 80%.

The latest data (FFY 02) show a dramatic change in retailers’ attitudes toward their obligation of responsible tobacco retailing. Today, Wisconsin has the lowest compliance rate (66.3%) and 38 states (and the District of Columbia) have compliance rates above 80%. Maryland has improved its compliance rate to 75%. However, Maryland still lags behind the nation: in FFY 2002, Maryland’s 75% compliance was the fourth lowest compliance rate in the nation as shown in Figure 5.14 on previous page.³⁷

Cessation of Tobacco Use

If Maryland is to achieve its vision of reducing tobacco use by 50%, it must not only succeed in reducing the number of young people that initiate smoking behaviors, it must also assist those who want to quit smoking. There is ample evidence that substantial numbers of Marylanders want to free themselves from their addiction to nicotine.

Smokers Want to Quit

In the fall 2000 MATS and MYTS baseline tobacco surveys, over one-half of current adult smokers stated that they would like to quit in the next six months. More than half reported that they had already tried, unsuccessfully, to quit during the previous 12 months. The top five reasons given for wanting to quit were: (1) to improve physical fitness, (2) concern about the health risks associated with smoking, (3) the health problems associated with smoking, (4) bad aesthetics (taste/looks/smell), and (5) the cost of tobacco.

A large number of Maryland youth who smoke want to quit too. Almost 52% of middle school youth and 49% of high school youth who currently smoke say that they would like to quit and over 66% of middle school and 59% of high school youth report that they have tried to quit smoking.

The benefit of quitting is clear. Cigarette smokers who

quit smoking before they turn 50 reduce their chance of dying in the next 15 years by half.³⁸

In the fall of 2000, Maryland was estimated to have a total of 903,458 youth and adults that were current users of at least one tobacco product. If, on average, 50% of tobacco users would like to quit, then Maryland has a potential tobacco-use cessation market of 465,229 individuals. On an annual basis, 10% of all smokers make use of full cessation services (counseling and pharmaceutical aids).³⁹ In Maryland, this translates to an annual demand for full cessation services of approximately 90,000 individuals.

Helping Smokers to Quit

Providing assistance to people who want to quit is neither easy, nor inexpensive. However, smoking-cessation is more cost-effective than other commonly provided clinical preventive services such as mammography, colon cancer screening, PAP tests, treatment of mild to moderate hypertension, and treatment of high cholesterol.^{40,41,42} The savings in reduced health care costs from the implementation of moderately priced, effective, cessation programs would pay for themselves within three to four years.⁴³

The Centers for Disease Control and Prevention recommends that state action on tobacco-use cessation include the following elements: (1) establishment of population-based counseling and treatment programs such as cessation helplines, (2) adoption of system changes as recommended by the AHCPR-sponsored cessation guidelines, (3) covering treatment for tobacco use under both public and private insurance, and (4) eliminating cost barriers to treatment for underserved populations, particularly the uninsured.⁴⁴

If Maryland is to succeed in helping those who want to sever their addiction to nicotine, it is critical that it implement these CDC recommendations. Maryland has made a start in this direction, as the state has begun to fund cessation programs in each county and Baltimore City (for a current list of cessation programs see <http://www.SmokingStopsHere.org>). But it must implement additional measures including a telephone quit/help line, advocating for coverage of cessation counseling by public and private insurance, and providing sufficient funding to meet the demand for cessation services in Maryland.

Current Efforts

The Maryland Department of Health & Mental Hygiene's Tobacco-Use Prevention and Cessation Programs

General Fund: Tobacco-Use Prevention and Cessation Program

Maryland initiated small tobacco-use prevention and cessation efforts in 1992 as part of the state's Cancer Initiative. Today, this program continues to provide resources to local health departments for smoking-cessation services, community organizing, community education, and outreach to minority, low-income, and low-educated populations. In addition, this program provides resources to local school systems for tobacco-use prevention curricula, instruction, staff training, and peer support initiatives like the Students Against Starting Smoking (SASS) clubs.

Federal CDC Grant:

National Tobacco Control Program

In 1993 the Centers for Disease Control and Prevention began providing funding to help states build capacity and infrastructure for comprehensive tobacco control, and to promote policy solutions to reduce tobacco use. The grant provides core funding to enhance partnership collaboration, mobilize communities, train community organizations, and conduct surveillance studies and media advocacy initiatives. Today, this grant complements and enhances all statewide efforts by working closely with Smoke Free Maryland (the statewide coalition) on statewide and local policy initiatives, funding grassroots and pilot tobacco projects and providing the necessary training programs for advocates and lay people. Some of the initiatives include policy promotion and training for smoking cessation, mobilizing little league, adult, and minor league sports venues to promote tobacco-free environments and lifestyles, providing training on "best practices" for college tobacco control programs, developing a tobacco control resource center on the campus of a historically black college (University of Maryland Eastern Shore), and supporting the Legal Resource Center efforts to localize policy development.

Cigarette Restitution Fund: Tobacco-Use Prevention and Cessation Program

The purpose of the program is to coordinate the state's use of the Cigarette Restitution Fund to address issues relating to tobacco-use prevention and cessation and to create a lasting legacy of public health initiatives that result in a reduction of tobacco use in the state and oth-

erwise benefit the health and welfare of the state's residents. The program consists of five components:

Statewide Public Health Component: The purpose of this component is to develop and implement statewide anti-tobacco initiatives that are consistent with the findings and recommendations of the 1999 Governor's Task Force to End Smoking in Maryland Task Force Report and the recommendations of the Centers for Disease Control and Prevention regarding best practices for comprehensive tobacco control programs as they relate to statewide programs, including programs that support the implementation of the Cigarette Restitutions Fund Program's Local Public Health Component.

Local Public Health Component: The purpose of this component is to maximize the effectiveness of anti-tobacco initiatives in the state by authorizing local health coalitions to develop and implement tobacco-use prevention and cessation programs in coordination with the DHMH. Funding comes from DHMH Local Tobacco Grants in support of: community-based programs, school-based programs, programs relating to enforcement of tobacco control laws, and cessation programs.

Counter-Marketing and Media Component: The purpose of this component is to coordinate a statewide counter-marketing and media campaign to counter tobacco advertisements and discourage the use of tobacco products.

Surveillance and Evaluation Component: The purpose of this component is to collect, analyze, and monitor data relating to tobacco use and tobacco-use prevention and cessation in the state; measure and evaluate the results of the program, including the results of each component of the program; conduct a baseline tobacco study; and conduct subsequent biennial tobacco studies.

Administrative Component: The purpose of this component is to provide the necessary administrative structure within DHMH for effective management of the program.

Legacy Grant: Youth Empowerment/Tobacco-Use Prevention Program

The American Legacy Foundation, created as a result of the national settlement with the tobacco industry, supports efforts across the nation to reduce tobacco use among youth and young adults. Maryland received

a grant to develop and implement a youth empowerment program to provide youth with the skills and forums needed to take action on their own to reduce tobacco use among their peers. Through this grant, nine youth coalitions are funded through community organizations. These groups conduct tobacco-use awareness and prevention activities in their jurisdictions including public service announcements, presentations at elementary and middle schools, and hosting tobacco-free sports challenges and smoke-free dining nights at local restaurants. Each youth coalition has a representative on a statewide Youth Advisory Board. This board has named Maryland's American Legacy Foundation program "Teens Rejecting Abusive Smoking Habits (T.R.A.S.H.)." T.R.A.S.H. organizes tobacco control training events for youth at state and local tobacco control conferences, developed a web site (www.marylandtrash.com) to increase awareness of youth tobacco control efforts, and is currently producing a youth cessation tool kit.

Nongovernmental Tobacco-Use Prevention and Cessation Efforts

Smoke-Free Maryland

Smoke-Free Maryland is a statewide coalition of more than 100 health, religious, and business organizations, as well as countless active individuals, working to reduce and prevent tobacco-induced death and disease. The coalition represents at least 500,000 Marylanders and works to reduce tobacco-induced illness and death by:

- advocating for significantly higher tobacco prices.
- preventing the sale of tobacco to minors.
- restricting targeted tobacco advertising.
- protecting workers and the public from second-hand smoke.
- helping smokers who want to quit get treatment.
- advocating for local government control over the sale, distribution, marketing, and use of tobacco products.

American Cancer Society

The American Cancer Society has developed several programs and planning tools related to tobacco-use prevention and cessation. "Communities of Excellence in Tobacco Control" is an American Cancer Society planning tool used to equip members of local coalitions with the skills and resources they need to serve as catalysts and leaders in the cause of tobacco control. A variety of advocacy, business, and health-related part-

ners who have a shared commitment to tobacco control and community mobilization are involved in this effort. In a nutshell, "Communities of Excellence in Tobacco Control" helps communities to:

- complete a tobacco control community assessment.
- form or strengthen a tobacco control coalition.
- create a tobacco control plan of action.

"Communities of Excellence in Tobacco Control" materials and workshops are available at local American Cancer Society offices.

"The Power of Choice" is a tobacco control tool kit created for teens by the American Cancer Society. It can be used to empower youth to join adults in making a difference in communities by preventing tobacco use among youth and increasing awareness about the powerful influence the tobacco industry has over youth. It contains suggested empowerment activities, meeting ideas, tip sheets, skill-building techniques, and suggests ways youth can stay active in community tobacco control activities. "The Power of Choice" is designed to complement the guide "Communities of Excellence in Tobacco Control." It focuses on connecting youth advocacy to tobacco control activities, impacting tobacco control policies, youth attitudes towards tobacco use, and environmental changes related to tobacco.

American Lung Association

Since 90 percent of smokers begin smoking before the age of 18, the American Lung Association targets youth with their tobacco-use prevention activities. Youth-based programs provide an opportunity to empower youth to serve as agents of change and advocates for tobacco-free communities and schools. Teens Against Tobacco Use (T.A.T.U.) has met with critical acclaim nationwide for its impact not only on students, but also on teens as teachers. T.A.T.U. trains teens to help younger children remain tobacco-free and is built on the same principles that are the cornerstone of school- and community-based service learning.

The American Lung Association's Tobacco Free School Environments is a program based on the Centers for Disease Control School Health Guidelines to Prevent Tobacco Use and Addiction. This program utilizes all seven components of the CDC guidelines that provide an ongoing educational environment about the hazards of tobacco and about how the tobacco industry markets its deadly products to youth. It also includes involv-

ing youth in programs like T.A.T.U. and in providing cessation programs for those youth who want to quit.

Toxic Soup is an American Lung Association program that gives kids a better understanding of the harmful chemicals that are found in tobacco products. Kids are given a list of chemical ingredients found in tobacco products and then shown dangerous household products that contain the same ingredients and that have warning labels on the containers highlighting the dangers of these chemicals. The point is that although the same chemical ingredients are found in tobacco, no warning labels are given on tobacco products.

The American Lung Association, in collaboration with West Virginia University, developed Not On Tobacco (N-O-T), a revolutionary new approach to help teens quit smoking. This program has been extensively field-tested in 15 sites nationwide with encouraging results in helping teens quit or reduce the number of cigarettes smoked. The program incorporates a life management skills approach that is applicable to any health risk behavior.

Freedom From Smoking® is an eight-session group clinic program led by trained experts from the American Lung Association. The program uses a positive behavior change approach that teaches the smoker how to become a nonsmoker. It provides key information on behavior modification, stress management, weight control, and staying smoke-free for good. The Freedom From Smoking® program has been extensively evaluated and has an average quit rate of 27% after one year. A seven-module version of the program is also available online and is free to those who want to quit smoking in the privacy of their homes. It provides the same high quality information as the group clinic program.

The Quit Kit is a free smoking-cessation packet offered by the American Lung Association and includes a booklet of tips for quitting successfully, a summary of nicotine replacement medications, strategies for weight control, and a listing of smoking-cessation programs in local communities.

The American Lung Association of Maryland's "Tobacco Smoke Hurts My Lungs..." is a public awareness campaign designed to 1) educate smokers, especially parents or guardians who smoke, about the effects of secondhand smoke on children's health and 2) encourage them to protect children from exposure. The message will affect change in the behavior of the target community and the Maryland smoking community at large.

American Heart Association

In order to reduce tobacco use, particularly among children, the American Heart Association (AHA) supports public policies in accordance with the following set of core principles for legislation:

- Provide significant funding for comprehensive public health education programs, including smoking cessation, counter-advertising, and state and local initiatives.
- Support significant price increases on tobacco products.
- Prohibit tobacco marketing and advertising, particularly that targeted at women, children, and minorities.
- Ban smoking in public places, including the workplace.
- Support significant, meaningful penalties on the tobacco industry for failure to reach targets for reducing tobacco use among youth.
- Oppose federal preemption of state and local statutes, and state preemption of local statutes.
- Support adequately funded and full FDA authority over the manufacture, sale, distribution, labeling, and promotion of tobacco.
- Support international tobacco control initiatives, including support for the World Health Organization's Framework Convention on Tobacco Control, and prohibit U.S. government activities that would facilitate marketing tobacco products overseas.
- Cease governmental financial support for the growth, promotion, and marketing of tobacco, and support the creation of programs to assist farmers and tobacco-growing regions to develop economic alternatives to tobacco.

Gaps in Tobacco-Use Prevention and Cessation in Maryland

Inadequate Funding of Tobacco-Use Prevention and Cessation Programs

The CDC has identified "best practices" for comprehensive state tobacco-use prevention and cessation programs, and the funding levels necessary to support such programs in each state. If Maryland is going to reduce the human and economic toll that tobacco use

causes, it is recommended that Maryland fully fund every component and element of its CDC model program. Although Maryland committed to such a program in legislation passed in the spring of 2000, the program has never been funded at even the minimum level recommended by the CDC, and available resources are directed elsewhere.

Tobacco Settlement Funds Not Prioritized for Reducing Tobacco-Related Disease

Maryland's settlement with the tobacco industry (to recover the cost of past medical services provided through Medicaid that were incurred as a result of tobacco-related disease) is the state's Cigarette Restitution Fund's sole revenue source. These proceeds, given their origin and the well-documented threat to the public health that tobacco use (and nicotine addiction) poses to our citizens, must first be used to reduce the human and economic toll that tobacco exacts before being committed to other worthwhile purposes. It is recommended that funding of Maryland's Tobacco-Use Prevention and Cessation Programs at no time be less than the minimum amount recommended by the CDC.

Lack of a Long-Term Commitment to Significantly Reduce Tobacco-Related Disease

Significant reductions in tobacco-related disease, in the costs of treating such disease, and in the tax burden resulting from these costs cannot occur without a significant reduction in tobacco use in the state. In turn, changes in tobacco-use behavior cannot occur without a programmatic policy effort by the state and its local communities. Such an effort requires adequate resources and a long-term bipartisan commitment to a healthier Maryland for all citizens. It is recommended that the state commit to its CDC-modeled Comprehensive Tobacco-Use Prevention and Cessation Program for a period of not less than 10 years, and, in any event, until a 50% reduction in tobacco use (from 2000) has been achieved.

Lack of Adequate Public Policy Support to Reduce Tobacco-Related Disease

Significant reductions in tobacco use, and the consequent improvement in the health and well being of all Maryland residents, cannot occur merely as a result of the efforts of Maryland's Tobacco-Use Prevention and Cessation Program. The CDC "Best Practices in Tobacco

Use Prevention" recognizes that such a comprehensive program must also be supported by the adoption of statewide and local public policies that complement and advance the vision of a healthier Maryland. It is recommended that the state and local communities support Maryland's programmatic effort with public policies that complement and further the vision, goals, and objectives of the program, including but not limited to: (1) preventing exposure to second-hand smoke in the workplace, (2) reducing children's exposure to secondhand smoke, (3) ensuring that all tobacco users who want to quit have access to affordable or free cessation services, (4) increasing the state excise tax on cigarettes to at least \$1.50 by 2007, (5) preventing retailers from selling tobacco products to youth under the age of 18, and (6) providing for continuous evaluation and improvement of state and local tobacco programs.

Lack of Funding for Tobacco-Use Cessation Research and Cancer Research

It is clear that over 50% of the Maryland youth and adults that currently use tobacco wish to quit. Once Maryland is fully funding its tobacco-use prevention and cessation programs, then additional funding should be directed to support behavioral research by the Academic Health Centers in Maryland for the development of even more effective tobacco-use cessation programs for all demographic groups. In addition, Maryland should continue to use tobacco settlement funds to support research into tobacco-related malignancies, diagnosis, prevention, and treatment.



Tobacco-Use Prevention and Cessation and Lung Cancer Goals, Objectives, and Strategies

Goals:

Substantially reduce tobacco use by Maryland adults and youth.

Substantially reduce youth and adult exposure to second-hand smoke.

Targets for Change

By 2008, reduce lung cancer mortality to a rate of no more than 57.3 per 100,000 persons in Maryland.

The Maryland baseline was 59.5 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Division of Health Statistics.

By 2008, reduce the proportion of Maryland middle school youth that currently smoke cigarettes to no more than 6.2%.

The Maryland baseline is 7.3%.

Source: Maryland Youth Tobacco Survey (2000).

By 2008, reduce the proportion of Maryland high school youth that currently smoke cigarettes to no more than 20.3%.

The Maryland baseline is 23.7%.

Source: Maryland Youth Tobacco Survey (2000).

By 2008, reduce the proportion of Maryland adults that currently smoke cigarettes to no more than 15 %.

The Maryland baseline is 17.5%.

Source: Maryland Adult Tobacco Survey (2000).

By 2008, increase the proportion of Maryland adults that would support a proposal to make all restaurants in their community smoke-free to 72.1%.

The Maryland baseline is 63.0%.

Source: Maryland Adult Tobacco Survey (2000).

Objective 1:

Fund Maryland's Comprehensive Tobacco-Use Prevention and Cessation Program at *least* at the minimum level recommended by the Centers for Disease Control and Prevention.

Strategies

1. Document the cost of tobacco-related disease in human and economic terms to the Maryland economy and its citizens.
2. Document the benefits of a comprehensive tobacco-use prevention and cessation program in reducing the human and economic toll tobacco use is exacting from Maryland.
3. Document the extent of the resources made available to the state of Maryland as a result of its settlement with the tobacco industry and the reasons for the lawsuit.
4. Document how Maryland is prioritizing its use of proceeds from the tobacco settlement.
5. Communicate these findings to interested citizens and key stakeholders.
6. Advocate for full funding of every component of Maryland's Comprehensive Tobacco-Use Prevention and Cessation Program, including, but not limited to, a comprehensive quit line to assist Marylander's in their attempts to quit; Maryland's mass media campaign to counteract tobacco industry marketing efforts; tobacco-use cessation and prevention programs; surveillance and evaluation activities; and the legal resource center that provides technical support for local tobacco control initiatives.

**Objective 2:**

Establish public policy that supports state and local bans on smoking in all public places and workplaces.

Strategies:

1. Ban smoking in all workplaces, including eating and drinking establishments.
2. Ban smoking at day-care facilities at all times when children may be present (closing the COMAR 07.04.01.33 loophole that prohibits smoking in family day-care facilities *only* while “engaged in care giving activities requiring direct physical contact...”).
3. Establish tobacco-free zones that prohibit the use of tobacco products by youth or adults on school and recreational properties at all times.
4. Explicitly permit local restrictions on smoking that are more stringent than statewide restrictions.

Objective 3:

Increase the excise tax on cigarettes to \$1.50.

Strategies:

1. Enact state legislation increasing the excise tax on cigarettes and other tobacco products. This is a proven strategy that will reduce the use of tobacco, particularly among underage youth. Unlike other proposals to increase taxes, this proposal is directly correlated with improving the health of Maryland citizens.

Objective 4:

Enact civil prohibition on the sale of tobacco to youth under 18 years of age.

Strategies:

1. Enact state legislation to permit civil agencies to enforce Maryland’s existing prohibition on the sale of tobacco products to youth less than eighteen years old, thereby relieving overburdened law enforcement agencies from this responsibility.
2. Civil enforcement must provide for a graduated series of penalties, against both the licensee and the person who makes the illegal sale. These penalties must culminate in a mandatory suspension of a cigarette retailer’s license to sell tobacco, and ultimately result in its revocation for chronic violators.
3. Enact state legislation requiring tobacco retailers to take reasonable steps to verify that a prospective purchaser is of legal age by demanding and reviewing photo-identification. ID must be demanded of all persons who appear to be under the age of 27 (the former FDA requirement).
4. Enact state legislation providing an affirmative defense for tobacco retailers who use electronic means to verify identification offered as proof of age in connection with the sale of tobacco products.
5. Enact state and local legislation that requires tobacco retailers to place all tobacco products beyond the reach of their customers absent the intervention of store personnel.
6. Educating tobacco retailers on any changes in the law and their responsibilities as tobacco retailers must be an integral part of any enforcement program.



7. Local communities must be explicitly permitted to adopt local restrictions that are more stringent than statewide restrictions.
8. Local governments should be encouraged to pass ordinances that make it easier to enforce youth access to tobacco laws.

Objective 5:

Ensure access to tobacco-use cessation services.

Strategies:

1. Enact state legislation mandating health insurance plans in Maryland cover tobacco-use cessation programs and products.
2. Implement the CDC-recommended statewide quit line to ensure that smokers who want to quit have access to help when they need it from wherever they live in the state.
3. Develop strategies to provide cessation products to the uninsured and underinsured.

Objective 6:

Enhance existing program activities.

Strategies:

1. Promote increased collaboration between all Maryland tobacco-use prevention and cessation programs to avoid duplication of resources and efforts.
2. Develop and promote a provider reminder and education program for smoking cessation.
3. Develop and promote tobacco-use cessation programs specifically aimed at college-age individuals and pregnant women.
4. Develop and promote education programs on the benefits of smoke-free homes (i.e. those with small children and/or asthmatics).
5. Continue to work to reduce patients' out-of-pocket costs for effective treatments for tobacco use and dependence, including the uninsured, underinsured, and college-age youth.
6. Improve existing enforcement of smoke-free schools.
7. Improve enforcement of existing local and state prohibitions on sale of tobacco to minors.
8. Develop and promote education programs for members of the judiciary and business community on the importance of enforcing youth access laws.
9. Continue and strengthen tobacco-use prevention education in grades K-12 as part of the Comprehensive Tobacco Use Prevention and Cessation Program.

**Objective 7:**

Continuously evaluate and improve state and local programs.

Strategies:

1. Develop and implement a formal evaluation plan to ensure the effective use and allocation of program resources.
2. Contract with an independent evaluator to assess the tobacco-use prevention and cessation programs.
3. Conduct biannual surveys of adult and youth tobacco-use behaviors at the statewide and county levels.
4. Conduct special population studies targeting high risk and targeted populations.
5. Develop a statewide data collection system for all elements of local tobacco grant activity.
6. Develop and disseminate user-friendly reports for a variety of audiences as survey data becomes available.
7. Develop and disseminate user-friendly reports of local tobacco control activities and local resource directories.
8. Encourage the reporting and dissemination of local best practices, information, data, and experiences.
9. Develop a recognition program for efforts of local jurisdictions.
10. Continue to refine and support the counter-marketing/media campaign.

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CHAPTER 6

DIET AND PHYSICAL ACTIVITY

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DIET AND PHYSICAL ACTIVITY

Maintenance of a nutritious diet, healthy weight, physical activity, and avoidance of alcoholic beverages may prevent as much as a third of all cancers (Figure 6.1).¹ Healthy diet, physical activity, and maintenance of healthy weight are also important for preventing other common chronic diseases such as heart disease, stroke, and diabetes. Most people find it very difficult to make substantial changes in their diets and activity levels. Parents also find it difficult to foster good dietary and activity habits in their children. Marylanders would be healthier in general and could experience a reduction in the notably high rates of cancers of the breast, prostate, and colorectum if even relatively small changes in eating and activity habits could be made and sustained.

This chapter will:

- describe the major diet and physical activity factors that contribute to high cancer rates in Maryland;
- discuss the individual and societal factors that contribute to the prevalence of these problems in Maryland; and
- propose objectives and strategies to reduce the occurrence of cancer in Maryland's citizens.

Diet and Physical Activity Factors Contributing to High Cancer Rates in Maryland

The following factors are likely contributors to Maryland's high cancer rates:

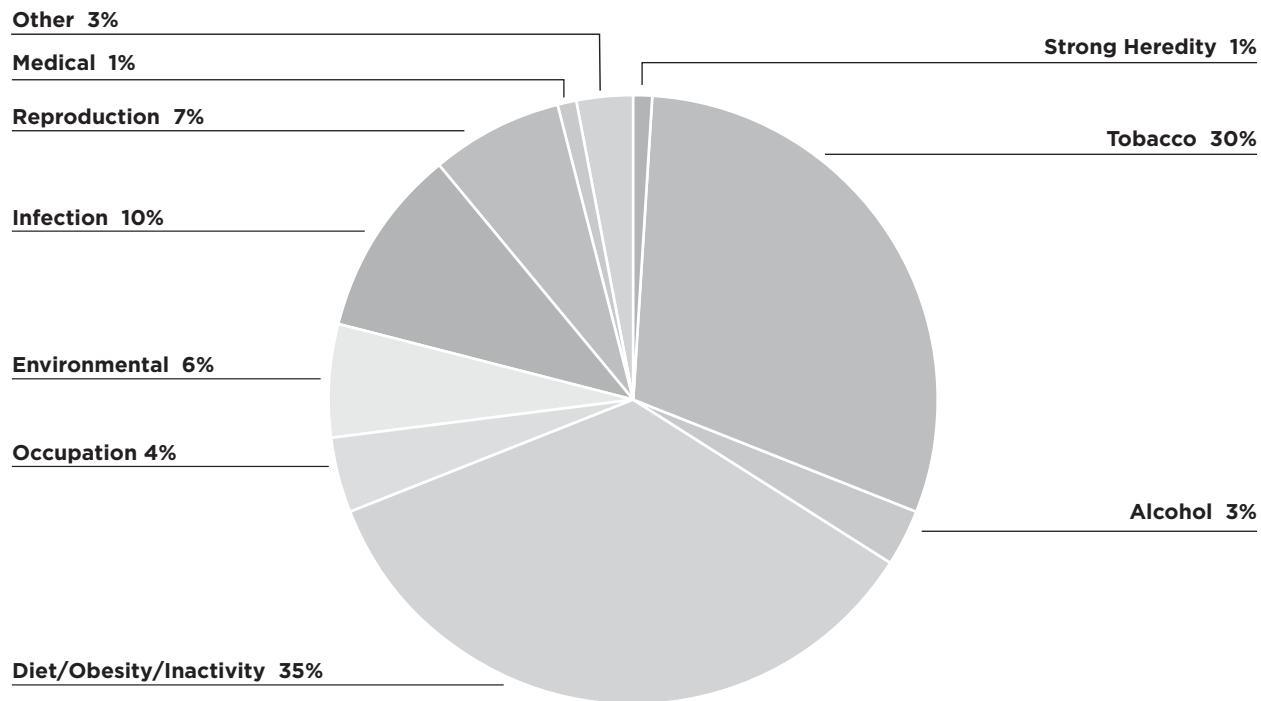
- Energy imbalance due to:
 - the consumption of too many calories
 - being overweight or obese
 - being physically inactive
- Suboptimal diet, including:
 - eating too few fruits and vegetables
 - eating too much red meat and processed meat
- Alcohol intake

These factors are important for four reasons:

- The scientific evidence supports them as major risk factors for cancer in general and for organ-specific cancers that are common in Maryland.
- Guidelines from governmental and national organizations, such as the American Cancer Society (ACS) and the American Institute for Cancer Research

Figure 6.1

**Proportion of Cancer Risk That is Attributable to Certain Exposures
in Developed Countries**



Source: Adapted from Doll R, Peto R. The causes of cancer: quantitative estimates of avoidable risks of cancer in the United States today. J Natl Cancer Inst 1981 Jun;66(6):1191-308.

(AICR), target these problems.

- The prevalence of these risk factors is high in Maryland. (Prevalence refers to the percentage of a population that is affected with a particular risk factor at a given time.)
- These risk factors are modifiable, making them targets for prevention as well as intervention.

Studies have shown that nutrition and physical activity influence cancer risk for several organs.^{2,3} Nutrition and physical activity are modifiable risk factors. In Maryland, 23,267 new cancer cases were diagnosed and 10,096 deaths were due to cancer in 1999.⁴ The most common among these are cancers of the lung and bronchus, colon and rectum, breast, and prostate. The incidence of, and mortality from, cancer is higher in Maryland compared to the United States for the period 1995–1999 (Table 6.1).

Energy Imbalance: Overweight, Obesity, and Physical Inactivity

Energy imbalance, that is, consuming too much energy (calories) for a person's body size and activity level, is difficult to measure directly in populations. The net effect of energy imbalance is weight gain in the form of fat. Body weight is not the best measure of energy imbalance; body mass index (BMI) is used as a surrogate measure.

BMI is body weight in kilograms divided by the square of height in meters. The chart shown in Figure 6.2 can be used to determine BMI. For example, a woman 5 feet 4 inches tall weighing 150 pounds has a BMI of 25.7 kg/m^2 . Widely used guidelines classify adults with a BMI of $25.0\text{--}29.9 \text{ kg/m}^2$ as overweight. Adults with a BMI of 30.0 kg/m^2 or more are classified as obese. Adults with a BMI of 25 kg/m^2 or above are at increased risk of overweight- and obesity-associated disease.⁵ In children, the definition of high BMI is age and sex specific. According to the U.S. Centers for Disease Control and Prevention, a child whose BMI is

Table 6.1
Incidence Rates for Selected Cancers in Maryland and the United States, 1995–1999

	All cancers		Colorectum		Breast	Prostate
	Male	Female	Male	Female	Female	Male
Maryland	610.7	442.2	69.7	52.0	141.7	189.3
U.S. SEER data	562.6	424.1	65.1	47.6	136.7	168.9

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Annual Cancer Report, CRF, DHMH, 2002 (Maryland rates); American Cancer Society, Cancer Facts & Figures, 2003 (U.S. rates).

above the 95th percentile for age is overweight.⁶ A child whose BMI is between the 85th and 95th percentile is at risk for becoming overweight. BMI is not a perfect measure of how fat, or adipose, a person is. For example, people who are very muscular may have a higher BMI. However, for most Marylanders higher BMI is a useful indicator of overweight and obesity.

Another anthropometric measure used to indicate energy imbalance and risk for overweight- and obesity-associated disease is waist circumference. Waist circumference over 40 inches in men and over 35 inches in women indicates increased risk of disease.

The prevalence of overweight and obesity has risen very rapidly in the U.S. and Maryland over the past decades. In 1990, 12% of Marylanders were considered to be obese. That prevalence increased to almost 20% in 2001.⁷ Obesity may increase the risk of cancer in general, and cancer of many common sites.⁸

Another component of energy imbalance is low activity levels. Regular physical activity is essential to prevent weight gain and to support weight loss. It has been estimated that 30 to 60 minutes of physical activity daily could reduce the risk of colon, breast, uterus, and prostate cancer by 20% to 40%.⁹ Based on review of epidemiological evidence, several organizations have developed recommendations for physical activity for adults and children. A report from the Institute of Medicine recommends one hour of moderately intense physical activity daily for adults to maintain energy balance.¹⁰ Specifically for cancer, the American Cancer Society (ACS) recommends 30 minutes or more of moderate activity at least five days per week for adults. For children ACS recommends 60 minutes or more of moderate activity (such as walking briskly) to vigorous activity (such as running) at least five days per week.¹¹ The ACS also indicates that for adults, 45 minutes or more may help to further decrease the risk of colon and breast

cancers. Regular physical exercise is of particular importance to limit the growing prevalence of obesity among children. The increase in obesity in children is in part due to decreased opportunities for exercise at home because of television and computer use and in school because of reduced frequency of physical education classes.¹²

Suboptimal Diet

The typical American diet in recent years has shifted to larger portion sizes with greater intake of processed and fast foods and animal-based proteins such as meats and dairy, and limited intake of fruits and vegetables. In this chapter, “diet” refers to the types and amounts of foods that a person eats rather than “being on a diet.” The current American dietary pattern is not optimal for reducing cancer risk. This chapter targets two aspects of suboptimal diet: low intake of fruits and vegetables and high intake of red meat and processed meat.

Intake of Fruits and Vegetables

The consumption of higher amounts of fruits and vegetables (e.g., five or more servings per day) has been associated with a lower risk of lung, oral, esophageal, stomach, or colon cancer in many epidemiological studies.^{13,14} Fruits and vegetables contain a wide array of vitamins, minerals, and antioxidants. Antioxidants reduce highly reactive oxygen-containing molecules that our bodies make themselves or to which we are exposed through the environment. Some antioxidants, like carotenoids, impart the spectrum of colors to fruits and vegetables. For example, tomatoes are red because they contain the carotenoid lycopene and carrots are orange because they contain the carotenoids alpha- and beta-carotene. Other nutrients important for good health are found in leafy green vegetables, like folic acid in spinach. Consumption of a variety of brightly colored fruits and vegetables will increase the range of antioxidant types and other essential nutrients that are ingested. Many research studies have examined which of these vitamins and minerals in fruits and vegetables

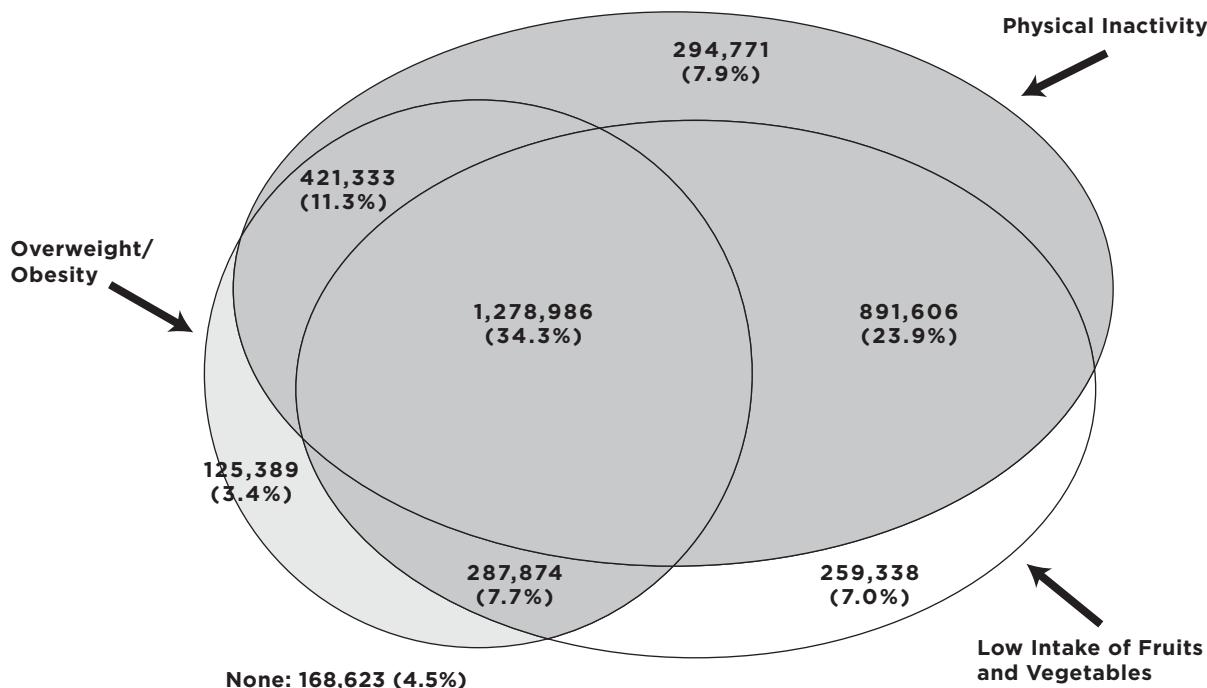
Figure 6.2
Body Mass Index (BMI) Chart

BMI	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35
Height	Weight (in pounds)																
4'10" (58")	91	96	100	105	110	115	119	124	129	134	138	143	148	153	158	162	167
4'11" (59")	94	99	104	109	114	119	124	128	133	138	143	148	153	158	163	168	173
5' (60")	97	102	107	112	118	123	128	133	138	143	148	153	158	163	168	174	179
5'1" (61")	100	106	111	116	122	127	132	137	143	148	153	158	164	169	174	180	185
5'2" (62")	104	109	115	120	126	131	136	142	147	153	158	164	169	175	180	186	191
5'3" (63")	107	113	118	124	130	135	141	146	152	158	163	169	175	180	186	191	197
5'4" (64")	110	116	122	128	134	140	145	151	157	163	169	174	180	186	192	197	204
5'5" (65")	114	120	126	132	138	144	150	156	162	168	174	180	186	192	198	204	210
5'6" (66")	118	124	130	136	142	148	155	161	167	173	179	186	192	198	204	210	216
5'7" (67")	121	127	134	140	146	153	159	166	172	178	185	191	198	204	211	217	223
5'8" (68")	125	131	138	144	151	158	164	171	177	184	190	197	203	210	216	223	230
5'9" (69")	128	135	142	149	155	162	169	176	182	189	196	203	209	216	223	230	236
5'10" (70")	132	139	146	153	160	167	174	181	188	195	202	209	216	222	229	236	243
5'11" (71")	136	143	150	157	165	172	179	186	193	200	208	215	222	229	236	243	250
6' (72")	140	147	154	162	169	177	184	191	199	206	213	221	228	235	242	250	258
6'1" (73")	144	151	159	166	174	182	189	197	204	212	219	227	235	242	250	257	265
6'2" (74")	148	155	163	171	179	186	194	202	210	218	225	233	241	249	256	264	272
6'3" (75")	152	160	168	176	184	192	200	208	216	224	232	240	248	256	264	272	279

Source: National Institutes of Health, National Heart, Lung, and Blood Institute (NHLBI). Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults: the Evidence Report. NIH Publication No. 98-4083. September 1998.

Figure 6.3

**Low Intake of Fruits and Vegetables, Physical Inactivity, and Overweight/Obesity:
Weighted Percentages for Maryland Adults 18 Years and Older**



Source: Maryland BRFSS, 2000.

are especially effective in reducing cancer risk. Observational studies suggest that those who consume higher amounts of vitamin C, beta-carotene, lycopene, selenium, and folic acid in their diets have a lower risk of cancer than those who consume lesser amounts. When some of these nutrients have been tested in clinical trials in which people were randomized to receive a supplement that contained a high amount of one specific nutrient, some findings have been disappointing,¹⁵ but other times interesting leads have emerged. For example, vitamin E and selenium are now being tested in SELECT, a very large clinical trial, to determine if they prevent prostate cancer.¹⁶ Taking all of the evidence together, consuming the recommended number of daily servings of fruit and vegetables of five or more is important for good health in general and may reduce cancer risk. Potatoes (e.g., baked potatoes, french fries, potato salad), which have a low content of desired nutrients but a high content of starch, should not be included as a fruit or vegetable when counting the number of servings of fruits and vegetables that are consumed. Some people at higher risk of cancer or who are unable to meet the recommended daily intake of certain nutrients from diet alone might consider talking to their doctor about whether they should take multi-

vitamins or single supplements.

Intake of Red Meat and Processed Meats

The consumption of red meat (such as beef) and processed meat (such as luncheon meats) have been associated with an increased risk of colorectal, prostate, and pancreatic cancer.^{17,18} For example, in a large U.S. cohort study, men who consumed red meat as a main dish at least five times per week had a three and a half-fold higher risk of colorectal cancer compared to men who never ate red meat as a main dish.¹⁹ The reasons for an association between red meat consumption and cancer risk are not fully understood, but several hypotheses have been suggested, including the high fat content of these foods. Heterocyclic aromatic amines, which are produced in meat cooked at high temperatures (grilling, barbecuing, and oven-broiling), have been shown to be carcinogenic in animal models, but results in humans are contradictory.²⁰ Nitrites in processed meats, which are added for preservation or improvement of color and taste, can be transformed into carcinogenic N-nitroso compounds by bacteria in the colon,²¹ which can interact with and damage DNA in colon cells, possibly causing tumors.²² At this point, these are only hypotheses. Diet may be improved by

replacement of some servings of red meat and processed meat with other protein sources such as tofu and other soy products and legumes (beans).

Alcohol Consumption

Alcohol consumption is a risk factor for cancers of the mouth, pharynx, larynx, esophagus, and liver, and may increase the risk of cancers of the colon, rectum, and breast.²³ Concurrent alcohol use magnifies the effects of tobacco on the risk for cancers of the upper digestive tract.²⁴ The International Agency for Research on Cancer has estimated that 75% of all cancers of the upper digestive tract are attributable to smoking and alcohol use.²⁵ Chronic, excessive alcohol consumption can cause liver cirrhosis, which increases the risk of liver cancer. In addition to these well-known associations, the risk of breast cancer appears to be increased in women who drink alcohol, even one alcoholic drink per day.²⁶ Although alcohol drinking clearly increases the risk of certain cancers, several population surveys indicate that moderate intake of alcohol may reduce the risk of cardiovascular events.²⁷ Nevertheless, the American Heart Association does not recommend the addition of alcohol as a cardioprotective substance, citing serious adverse consequences of alcohol intake including hypertension, liver damage, increased risk for breast cancer, physical abuse, and vehicular accidents.²⁸ Both the American Cancer Society and the American Heart Association recommend that those who do not currently drink alcoholic beverages should not start drinking, and those who do drink should limit their consumption.^{29,30}

Prevalence of Risk Factors in Maryland

The primary source of information regarding the prevalence of health risk factors for U.S. and Maryland adults is the Behavioral Risk Factor Surveillance System

(BRFSS). Data on overweight and obesity, physical activity, fruit and vegetable consumption, and alcoholic beverage consumption, but not red meat or processed meat, is collected in the BRFSS. Unless otherwise stated, the statistics in this section are from the Maryland BRFSS.³¹ Similar information for adolescents is available for the U.S. population as a whole, but not for Maryland adolescents specifically; instead we present data from the CDC's Youth Risk Behavioral Surveillance System (YRBSS) for adolescents in the United States.

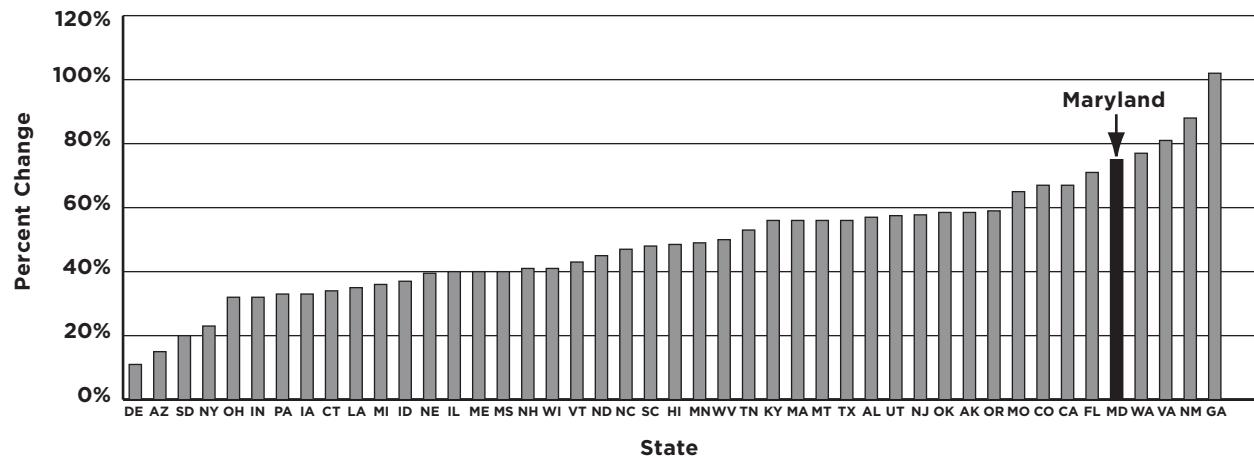
The prevalence of risk factors such as overweight and obesity, physical inactivity, and low intake of fruits and vegetables is very high in Maryland and this prevalence is often found in overlapping populations. Figure 6.3 illustrates where low intake of fruits and vegetables, physical inactivity, and overweight/obesity are found either alone or in combination with the other factors. Only 4.5% of the Maryland population age 18 years and older lack all three of these risk factors. About 18.3% had a single risk factor, with physical inactivity being the most common of the three risk factors (7.9%). 34.3% of the population had all three risk factors, while the remainder exhibited two of the risk factors. The combination of low intake of fruits and vegetables plus physical inactivity was the most frequent clustering of two risk factors (23.9%).

Table 6.2 indicates the prevalence of healthy diet and physical activity factors among Maryland adults from 1996 to 2000. The percent of Marylanders at a healthy weight appears to be declining steadily, going from 48.2% in 1996 to 43.3% 2000. Overall, the prevalence of regular or sustained physical activity and consumption of fruits and vegetables appear to be increasing. However, these trends show inconsistent increases over time, with the most recent prevalence statistic available (2000) being less than the prevalence of these behaviors in 1998.

**Table 6.2
Prevalence of Healthy Weight, Physical Activity, and Adequate Consumption of Fruits and Vegetables Among Maryland Adults, 1996, 1998, 2000**

	1996	1998	2000
Healthy weight ($18.5 \leq \text{BMI} \leq 24.9$)	48.2	44.5	43.3
Regular or sustained physical activity	13.3	25.8	22.3
Consumption of five or more fruits and vegetables per day	24.7	30.1	27.4

Figure 6.4
Percent Change in Prevalence of Obesity in Adults, 1991 to 1998



No information available for AR, DC, KS, NV, RI, or WY.

Data source: Mokdad AH, Serdula MK, Dietz WH, Bowman BA, Marks JS, Koplan JP. The spread of the obesity epidemic in the United States, 1991–1998. JAMA. 1999 Oct 27;282(16):1519–22.

Overweight and Obesity

The prevalence of overweight and obesity among Marylanders has been increasing steadily over the last 10 years as indicated by the BRFSS. From 1990 to 2000, the prevalence of overweight increased from 31% to 36% and the prevalence of obesity in Maryland nearly doubled, increasing from 12% to 20% (Figure 6.5). Between 1991 and 1998, Maryland had one of the largest percent increases in obesity of all states (Figure 6.4). In 2001, almost 20% of Maryland adults were obese (BMI of 30 kg/m^2 or greater) and more than 37% were overweight (BMI of $25\text{--}29.9 \text{ kg/m}^2$). Western Maryland, Baltimore City, Prince George's County, and parts of the Eastern Shore have more than 20% of their residents classified as obese. The prevalence of overweight and obesity in Maryland is fairly similar to national rates. For the time period 1996 to 2001, 55% of Marylanders were either overweight or obese. In 2000, about 57% of Americans were overweight or obese.³²

The prevalence of overweight and obesity increases with age. In Maryland in 2001, 15.6% of those 18–24 years of age were obese. The prevalence of obesity gradually increases with age, with 27% of those 55–64 being obese. The same trend is seen in prevalence of overweight in Maryland. Approximately 21% of those 18–24 years of age were overweight in 2001, and this increased to 36.3% in those 25–34 and 44.9% of those 65–74. About 65% of those 65–74 years of age are either overweight or obese.

Physical Inactivity

Nationally, the median proportion of the population with no regular or sustained physical activity was 78% in 2000.³³ Maryland's rate is very similar to the nation's, also having about 78% of its population reporting no regular or sustained physical activity in 2000. The proportion of Marylanders reporting no regular or sustained physical activity was higher among women than men and higher among blacks than whites in 2000. In addition, the prevalence of physical inactivity was higher among persons with less than a high school diploma and persons with a family income of less than \$15,000.

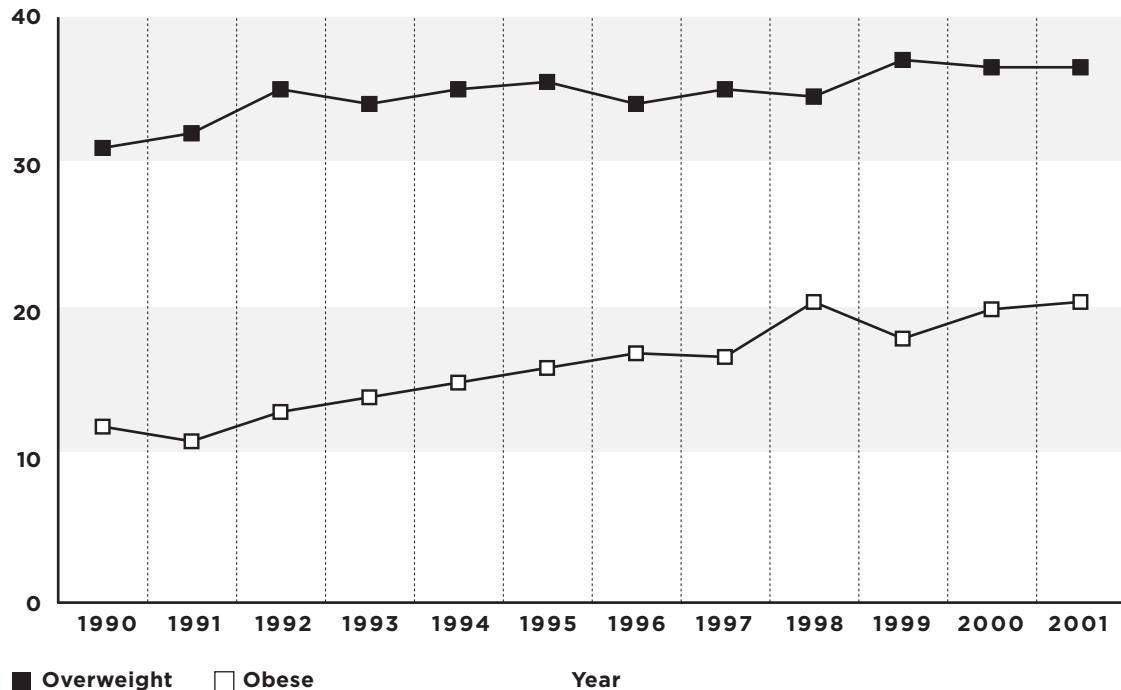
Inadequate Consumption of Fruits and Vegetables

In 2000, 27.4% of Maryland adults reported eating five or more servings of fruits and vegetables per day. This is slightly better than the U.S. as a whole; nationally, 23.1% of the population reported eating five or more servings of fruits and vegetables per day in 2000.³⁴ The age group with the lowest proportion consuming five or more servings of fruits and vegetables per day were adults ages 25–34. The proportion of Maryland adults who reported eating five or more servings of fruits and vegetables per day gradually increases with ages 35 and older.

Alcohol Consumption

In Maryland in 1999, 56% of adult men and 73.5% of

Figure 6.5
Prevalence of Overweight and Obesity in Maryland, 1990-2001



Data source: CDC BRFSS.

All respondents 18 and older gave weight and height. This information was used to calculate BMI.
 BMI 25 to 29.9 is defined as overweight and 30 or greater is defined as obese.

women reported that they never drank alcohol, or drank alcohol less than once a week. Nearly 72% of blacks reported that they never or rarely drank alcohol during this same year, compared with 62% of whites and 60.5% of Hispanics. Never or rarely (less than once a week) drinking alcohol is more prevalent among individuals with lower educational attainment and lower income. Thus, drinking alcohol once a week or more is more prevalent among more highly educated, higher income-earning Marylanders.

Prevalence of Risk Factors Among Youth

Very little information is available regarding the prevalence of risk factors among Maryland youth because Maryland does not participate in the CDC's Youth Risk Behavior Surveillance System (YRBSS). Nationally, 10% of adolescents were overweight in 2000, and another 14% were at risk for becoming overweight.³⁵ Also, 74% of U.S. adolescents did not participate in moderate physical activity on five or more days of the week.³⁶ In addition, a very large proportion of American adolescents (79%) ate less than five servings of fruits and vegetables per day during the preceding

seven days.³⁷ Because Maryland is very similar to the nation regarding the prevalence of these risk factors among adults, there is reason to believe that the prevalence of overweight and obesity, physical inactivity, and low intake of fruits and vegetables among Maryland youth are comparable to those nationwide, and therefore are cause for concern.

Disparities

In Maryland, diet- and activity-related risk factors other than alcohol consumption are more likely to occur among minorities and in low-income and less educated populations. This suggests the need for targeted interventions for these populations.

For example, the prevalence of overweight and obesity is higher among blacks than whites. In addition, blacks, persons with less than a high school diploma, and persons with an income of less than \$15,000 are less likely to be active than whites, persons who are college graduates, and persons who have an income of greater than \$75,000. These trends are similar for inadequate consumption of fruits and vegetables.

Summary of Prevalence of Risk Factors

The prevalence of overweight and obesity, physical inactivity, and inadequate consumption of fruits and vegetables is very high among Marylanders. More than 34% of Maryland adults exhibit all three of these risk factors. There is considerable need to address the epidemic of obesity and related risk factors as part of the effort to reduce the burden of cancer in Maryland. Individuals should weigh the risks and benefits of alcohol consumption with their physician's guidance.

Individual and Societal Factors Contributing to the Prevalence of Diet and Physical Activity Risk Factors in Maryland

The problems of overweight and obesity, inactivity, low intake of fruits and vegetables, and high intake of red and processed meat are multifactorial and may stem from behaviors, inaccurate or missing information, and other perceived and actual barriers. There are numerous sources of influence on these factors (Figure 6.6) ranging from individuals, their families, and their neighborhoods through government, health institutions, and other institutions. What follow are several examples of factors contributing to unhealthy diet and physical inactivity, some of which are societal, others of which are more individual in nature. Fortunately, many of these contributing factors are targets for intervention at many points in their trajectory of influence.

Individuals, Families, and Communities

Individuals and families may lack adequate knowledge about the benefits of a healthful diet and physical activity on cancer risk. In addition, a lack of financial resources may limit options for the preparation of healthy meals. Communities may lack safe sidewalks and bicycle paths, lessening the chance that individuals and families will walk and bicycle to work, to run errands, or for leisure-time outings.

One major barrier to increased physical activity appears to be the public's need for convenience and avoidance of strenuous activity. Escalators and elevators have replaced the need to take stairs. Parking lots are located close to workplaces. Work is often desk-

bound with little chance of physical activity. Television, video, and computer games tend to occupy much of leisure time. Transportation is nearly always achieved by personal automobile or some form of mass transit; one survey indicated that only 3.7% of Americans commute to work by bicycle or walking.³⁸

On the positive side, individuals, families, and communities can be a powerful force for effecting change. Neighbors can join together to demand sidewalks and playgrounds in their neighborhoods. In addition to advocating for safe, alternative means for transportation, families can bring their concerns to local school health advisory councils. Here families can advocate for school health education on nutrition and physical activity, daily physical education, and increasing healthy choices in school meals and vending machines.

Institutions Other than Health-Related

Food Purveyors

Fast foods are designed to be appealing to the palate. At the same time, they are calorie-dense, low in fruits and vegetables, and high in red and processed meats. Offering larger portions for a relatively small increase in cost to the consumer allows retailers to maximize profits since the increase in production cost is minimal.

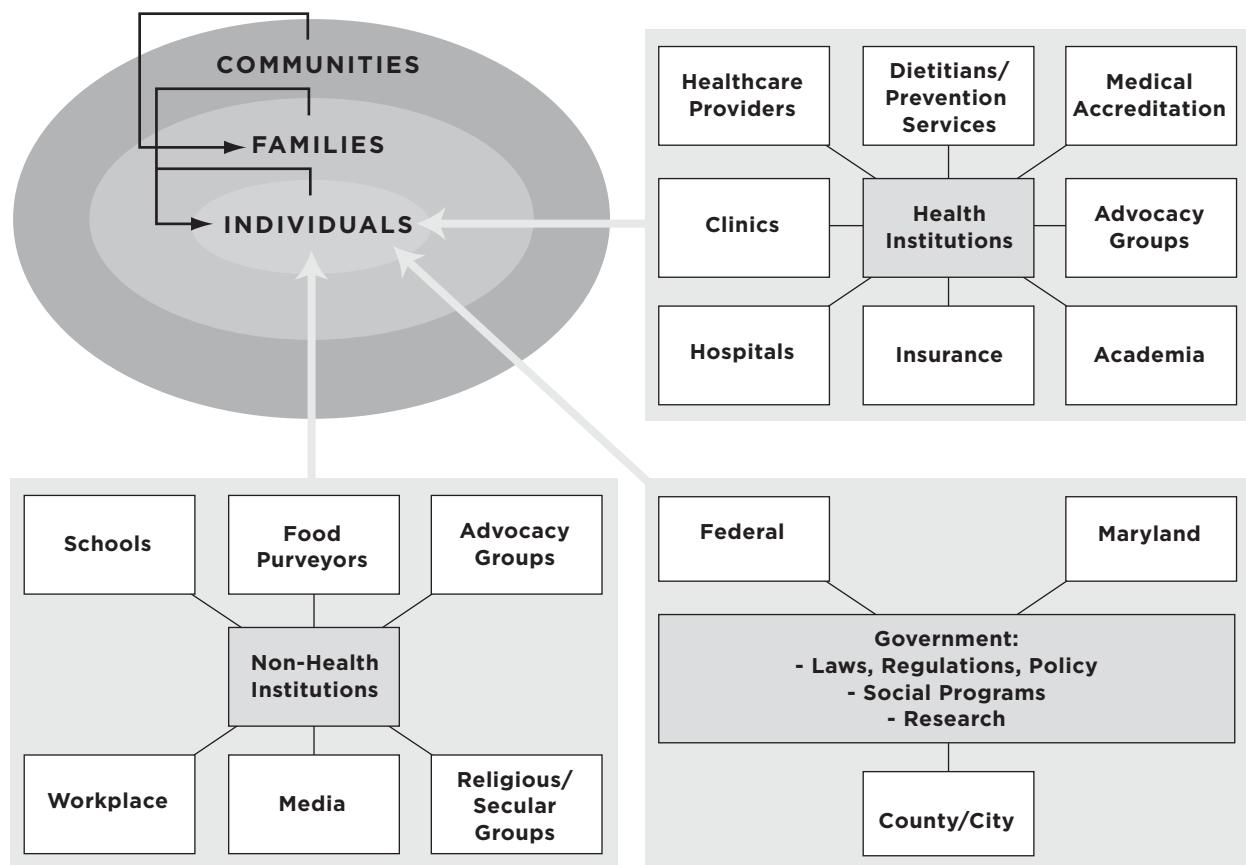
Nationwide there has been a dramatic increase in the consumption of food prepared away from home. In 1970 about 34% of the food dollar was spent on food eaten away from home. This increased to 47% by the late 1990s.³⁹ When Americans eat out, the portion size tends to be much larger than necessary to satisfy nutrient and energy needs. One recent survey concluded, "the sizes of current marketplace foods almost universally exceed the sizes of those offered in the past."⁴⁰

Schools

Schools contribute to the problems of obesity, inactivity, and suboptimal diet because of the limited frequency of physical education classes, inconsistent nutrition education, the availability of high-calorie, low-nutrient density foods and beverages in campus vending machines, and possibly suboptimal school lunches (in particular, a la carte items).

The decrease in activity among youth may be due in part to fewer hours spent in school-based physical education. Between 1991 and 1995, nationwide daily attendance in physical education classes for children in grades 9–12 decreased from 41.6% to 25.4%.

Figure 6.6
Sources of Influence on Diet and Physical Activity



Source: Developed by the Diet and Physical Activity Committee of the Maryland Comprehensive Cancer Control Plan.

However, on a positive note, from 1995 to 2001 the percent of students enrolled in a daily physical education class increased from 25.4% to 32.2%.⁴¹

Physical education curricula vary widely by state and even by local district. Maryland law requires that an instructional program in physical education be in place *each year* for all students in grades K–8. However, for grades 9–12, the requirement is much less stringent; each local school system must offer a physical education program that will enable students to meet graduation requirements and to select physical education electives.⁴² The Maryland physical education program should provide “individualized, developmentally appropriate, and personally challenging” instruction that also “provides for the diversity of student needs, abilities, and interests.”⁴³ While these provisions are admirable, they are somewhat irrelevant given that only 1/2 credit of physical education is required to graduate from a public school in Maryland.⁴⁴

Health education requirements for Maryland youth

attending public schools are similar to those for physical education. For grades K–8, each local school system must provide an instructional program in comprehensive health education each year for students in all grades.⁴⁵ However, for grades 9–12, the health education requirement is similarly less stringent; school systems must only provide health education to allow students to meet graduation requirements and select electives.⁴⁶ Again, only 1/2 credit of health education is needed for graduation.⁴⁷ Content requirements for health education are not specified in Maryland law, only that the health education instructional program be “comprehensive” in nature.⁴⁸ Generally, nutrition education is included in the comprehensive health education program, although the degree that nutrition education is taught in the classroom varies with the teacher’s experience and background. Teachers are given class plans, resources, and workshops to encourage nutrition instruction. The Maryland State Department of Education (MSDE) School and Community Nutrition Programs Branch trains teachers to encourage healthy behaviors. Team Nutrition

Grants are given to school programs to use for nutrition resources and encourages the involvement of the community, parents, health educators, and school administrators.

Because schools are a primary source of information for children and adolescents, educators can play a critical role in providing students with valuable messages in the classroom on the benefits of diet and physical activity in avoiding cancer. Students can then convey what they have learned to their families. Educators could provide brief, grade-appropriate education sessions on: What is cancer? What are its causes? How does healthy eating and physical activity reduce risk? Field trips to the produce section of supermarkets and development of school vegetable gardens could broaden students' exposure to healthy food options.

MSDE administers food and nutrition programs according to federal law and the implementing regulations.⁴⁹ In addition, Maryland has developed a policy on the availability of competitive foods and foods of minimal nutritional value in schools. Competitive food sales and vending machines are not to operate from 12 midnight through the last lunch period at each school.⁵⁰ Unfortunately, this policy is often found unenforced by MSDE school meals reviewers. More stringent means of enforcement are required for such policies, in addition to the development of alternative sources of revenue for schools to compensate for revenues otherwise provided by vendors.

Given the alarmingly high rates of overweight and obesity, low rates of physical activity, and general poor nutrition among America's youth, there is a significant need to target children with interventions designed to decrease the prevalence of these risk factors. Children spend a significant proportion of their time in school; thus, school curricula and food availability within schools likely have a large impact on the health of children.

Workplaces

Workplaces may contribute to the problems of obesity, inactivity, and suboptimal diet when there is a lack of activity breaks, a lack of employee wellness programs, and a lack of healthy food at work-related meetings and functions. However, by creating a culture favorable to physical activity and healthy eating, workplaces can improve the quality of life of their employees and reduce costs associated with employee illness.

Over 130 million Americans are in the workforce and employees spend the majority of their day at work.⁵¹

Much of the time workers are sedentary due in part to technological advances that have reduced the need for physical labor. In addition, the food and beverage selections in cafeterias and vending machines, as well as those served at meetings or events, often do not balance more healthful with less healthful options. Because physical inactivity and poor dietary practices or choices are the reality at most worksites, employers and providers could incorporate health promotion initiatives and environmental changes to improve the health of employees while also reducing costs.

According to the Wellness Councils of America, employers can take "aggressive action toward reducing health care utilization and containing costs by taking on a health promotion program."⁵² Policies and programs targeting healthful eating, physical activity, and weight loss or maintenance strategies are integral components of such wellness or health promotion initiatives. Research finds notable clinical and cost outcomes from employee wellness or health promotion programming, including lower health care costs, reduced absenteeism, reduced employee turnover, and increased productivity.^{53,54,55,56} More specifically, an analysis of 10 major studies found that the cost/benefit ratio of worksite health promotion programs ranged from 1:2.05 to 1:5.96, on average.⁵⁷ Worksite fitness programs, in particular, are associated with lower health care costs as well as improved health-related fitness.^{58,59} Employers adopting health promotion programming can also benefit from an improved public image, higher employee recruitment and retention, and improved employee morale.^{60,61} In summary, employers and providers can send a powerful message to employees and the community by not only promoting a healthful lifestyle, but by providing opportunities for these behaviors to be adopted and maintained through health promotion programming and environmental changes.

Health Institutions

Hospitals and Other Health Care Facilities

Even institutions that provide health care contribute to the problems of obesity and suboptimal diet. Many hospitals now have on-site fast food venues; even if they do not offer fast food, the foods and beverages available in health care facilities can be limited and prohibit consumers and employees, including health care providers, from making healthful and balanced choices.

Health Care Providers and Health Insurance Agencies

In the modern world of managed care, health care

providers may not have the time to discuss with their patients the benefits of maintaining a healthy weight, diet, and level of physical activity, despite the overwhelming prevalence of obesity and co-morbidities related to obesity.⁶² Nutrition counseling that includes encouragement of physical activity can be helpful in the promotion of a healthy diet and lifestyle.^{63,64} However, the U.S. Preventive Services Task Force (USPSTF) has concluded that “there is insufficient evidence to recommend for or against routine behavioral counseling to promote a healthy diet in unselected patients in primary care settings.”⁶⁵ Conversely, the USPSTF *does* recommend “intensive behavioral dietary counseling for adult patients with hyperlipidemia and other known risk factors for cardiovascular and diet-related chronic disease.”⁶⁶ However, preventive services, including nutrition counseling, are costly. Reimbursement for nutrition therapy exists with private health insurance plans on a limited basis and Medicare coverage for preventative nutrition and activity does not exist. Inadequate provider reimbursement for these preventive services may limit the referral of patients who would benefit from such services and those referred for these services may choose not to use those services for financial reasons.

On the positive side, health care providers wield much influence with patients, as they are the most trusted sources of information on healthful life choices for some populations. Patients look to their providers for guidance and often view them as role models. With expanded and more extensive reimbursement options, health care providers and their clients may be more likely to utilize the services of nutrition and exercise professionals to improve their own health, diet, and lifestyle. Health care providers utilizing and promoting these services via referrals can provide a positive image that their clients can observe, as they change their own habits and lifestyles.

Academia

Academia is an important influence on these issues because it can generate new research on the problems at hand. There is no systematic collection of information on the knowledge, attitudes, and beliefs of Maryland residents regarding the relationship of diet and physical activity to the prevention of cancer. In addition, if Maryland continues to decline to participate in the national Youth Risk Behavior Surveillance System, the state should consider an alternative method of obtaining information from children and youth similar to the YRBSS. At minimum, the survey

should measure diet, physical activity, height, and weight among children and youth, as well as their knowledge, attitudes, and beliefs regarding healthy diet and activity levels in relation to good health. State policymakers may then use this information to develop a state plan for diet and physical activity that would establish goals, objectives, and timelines for changes that would provide optimal nutrition and physical activity for Maryland residents.

Surveys administered to adults that cover the following topics and questions would greatly benefit the development of effective public policy:

- What is the average citizen’s opinion regarding diet and cancer? What is her/his view of the nature of that relationship? Is food seen as a source of environmental contamination that causes cancer or a source of nutrients that have protective qualities?
- Have individuals’ care providers discussed diet and physical activity as protective?
- What are the knowledge levels, attitudes, and beliefs about diet and physical activity and cancer among health professionals? Do providers know that diet and physical activity may reduce the risk of cancer? How often do they speak to their patients about this?
- What are the barriers to counseling patients about diet and physical activity, such as time, reimbursement, or beliefs that such counseling would be futile?

Interventionists

Interventions are efforts that impact the problems of obesity, inactivity, and suboptimal diet. Interventionists may work in any of the sources of influence and their interventions may be applied at the individual or societal level. Interventionists cannot be effective if they do not know the barriers to healthy eating and activity and if they are not aware of the knowledge levels, attitudes, and beliefs of citizens and providers about prevention of cancer through healthy diet and activity. Thus, the surveys described above are vitally important.

Government

Federal, state, and local governments have a major influence on the health and well-being of Maryland residents by mandating laws, regulations, and policies. These laws, regulations, and policies influence (both directly and indirectly) individuals, families, communi-

ties, and health care and other institutions. At all levels the government executes social programs, some of which provide food and health care. Along with academia and non-profit cancer research groups, governments conduct research on the role of obesity, inactivity, suboptimal diet, and alcohol use on risk of cancer.

For example, government is uniquely positioned to positively influence school curricula on nutrition and physical activity and on the nutrition labeling on prepared foods purchased in the grocery store and in fast-food establishments.

Current Efforts

Fortunately, there are several statewide programs designed to improve the nutrition and physical activity habits of Marylanders. “5 A Day for Better Health” is part of a national public-private partnership between government and industry, designed to increase Americans’ intake of fruits and vegetables to five or more servings a day by the year 2010. “5 A Day” informs consumers that eating fruits and vegetables can improve health and reduce the risk of cancer and other diseases, including heart disease, hypertension, diabetes, and macular degeneration. The Maryland Department of Health & Mental Hygiene (DHMH) is licensed by the National Cancer Institute to participate in the “5 A Day for Better Health” program. Maryland “5 A Day” efforts include a variety of educational and training activities and maintenance of partnerships, such as with the Maryland Department of Agriculture, which enable seniors and low-income families to purchase fruits and vegetables at reduced costs. These activities are implemented in schools, day care centers, work-sites, grocery stores, community sites, and even smoking cessation programs.

The ACS provides a variety of programs, tools, and technical assistance to aid Marylanders in eating right, being active, and maintaining a healthy weight. For example, “Body and Soul: A Celebration of Healthy Living” targets African-American church congregations. The goal of the program is to increase daily fruit and vegetable consumption to reduce cancer and other disease risks. “Active for Life” is a flexible 10-week worksite program that encourages employees to participate in moderate physical activity through goal setting, teamwork, and incentives. Based on the “Stages of Change Theory,” employees learn new skills and gain social support as they reach for their personal physical activity goal.

While not intended specifically for cancer prevention, the American Heart Association supports public policies designed to increase physical activity and maintain healthy weight among citizens, including the following recommendations:

- Ensure the incorporation of physical activity as a major component of appropriate disease prevention and health promotion efforts in state and federal agencies.
- Mandate appropriate, quality, school-site physical activity programs that comply with American Heart Association recommended guidelines.
- Encourage worksite physical activity programs.
- Seek opportunities to highlight the importance of physical activity in transportation policy.
- Advocate for “livable communities” and how they promote physical activity.
- Support and encourage quality physical activity and nutrition programs and policies to treat and prevent obesity.

A variety of other nutrition and activity resources exist but may not be implemented widely in Maryland. Efforts should be made to make citizens more aware of existing programs and resources in Maryland. In addition to the efforts mentioned above, a list of resources available in Maryland can be found at http://www.marylandcancerplan.org/diet_resources.html.

Healthy People 2010

Objectives⁶⁷

The following are select Healthy People 2010 objectives related to diet and physical activity:

Objective:

Increase the proportion of adults who are at a healthy weight to 60%.

The U.S. Baseline: 42% of adults aged 20 years and older were at a healthy weight (defined as a BMI of 18.5–25kg/m²) in 1988–1994 (age-adjusted to the year 2000 standard population).

Objective:

Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least 30 minutes per day to 30%.

The U.S. Baseline: 15% of adults aged 18 years and older engaged in moderate physical activity for at least 30 minutes five or more days per week in 1997 (age-adjusted to the year 2000 standard population).

Objective:

Increase the proportion of persons aged two years and older who consume at least three daily servings of vegetables, with at least one-third being dark green or orange vegetables, to 50%.

The U.S. Baseline: 3% of persons aged two years and older consumed at least three daily servings of vegetables, with at least one-third of these servings being dark green or orange vegetables, in 1994–1996 (age-adjusted to the year 2000 standard population).

Objective:

Increase the proportion of persons aged two years and older who consume at least two daily servings of fruit to 75%.

The U.S. Baseline: 28% of persons aged two years and older consumed at least two daily servings of fruit in 1994–1996 (age-adjusted to the year 2000 standard population).



Diet and Physical Activity Goals, Objectives, and Strategies

Goal:

Reduce the burden of cancer in Maryland through the promotion of healthy diet, healthy weight, and physical activity as a means of cancer prevention.

Targets for Change

These measurable objectives represent modest, population-based targets. It is important to note that continued lowering of BMI within the normal range, increasing physical activity, and increasing consumption of fruits and vegetables will likely reduce cancer risk even further.

1. By 2008, increase the percent of Marylanders with a BMI in the normal range (18.5 to 24.9 kg/m^2) to 50%.

The Maryland baseline was 43.3% in 2000.

Source: BRFSS.

2. By 2008, increase the percent of Marylanders participating in regular and sustained physical activity.

The Maryland baseline was 22% in 2000.

Source: BRFSS.

3. By 2008, increase the percent of Marylanders consuming 5 or more servings of fruits and vegetables per day to 33%.

The Maryland baseline was 27.4% in 2000.

Source: BRFSS.

Objective 1:

Increase awareness of and demonstrate healthy eating and physical activity patterns among Maryland families and communities.

Strategies:

1. Identify and implement existing effective programs for intervention to improve healthy eating and physical activity targeted to youth, young adults, adults, and health care providers. Where gaps exist, design and implement programs based on knowledge, attitudes, and beliefs surveys.
2. Convey simple and culturally appropriate messages, including but not limited to content such as:

What does a healthful plate of food look like?

What is a healthful portion size?

What to choose when eating out?

What counts as a serving of fruits and vegetables?

What counts as physical activity?

How does healthy eating and physical activity reduce cancer risk?

3. Develop and implement programs that result in healthy diet, healthy weight, and healthy physical activity with an emphasis on children, youth, and their families.
4. Develop information for use by local advocates to help persuade local boards of education to provide optimal school meals and physical activity for school and after-school programs.



5. Support communities in grassroots advocacy for activities such as access to healthy food in schools and neighborhoods, development of sidewalks and trails for biking and hiking, monitoring upkeep of playgrounds and parks, the addition of safety and lighting features to outdoor recreational areas, and the addition of nutrient labeling for fast foods and restaurant menus.
6. Promote farmers' markets, school and community gardens, and Community Supported Agriculture.
7. Promote healthy eating and physical activity through community groups such as the ACS's "Body and Soul" program within African-American churches.
8. Work with food purveyors to open and maintain grocery stores in urban settings.
9. Enhance links among existing food programs, including WIC and 5 A Day with local farmers' markets.
10. Dedicate funding and resources to enhance and create new sidewalks, trails, playgrounds, and parks and add lighting and safety features to these areas.
11. Allow public access to school tracks, courts, gymnasiums, and other recreational facilities.
12. Build a partnership among planning agencies, parks and recreation departments, and health departments to educate the planning agencies on the health benefits of physical activity and the importance of walking/bicycle trails.

Objective 2:

Increase the prevalence of healthy diet, healthy weight, and physical activity among Maryland youth.

Strategies:

1. Evaluate the effectiveness of existing Maryland laws pertaining to primary and secondary physical education and comprehensive health education.
2. Mandate specific and consistent objectives for nutrition and physical activity education in grades K–12.
3. Compile a comprehensive list of existing nutrition-related curricula and enhance educators' access to these curricula; seek foundation support for curricula implementation.
4. Support the inclusion of questions pertaining to nutrition and physical activity on required Maryland assessment exams.
5. Promote interdisciplinary learning experiences to improve diet and exercise such as field trips to the produce section of supermarkets, development of school gardens, and stretch or dance breaks during the school day outside of standard physical education.
6. Provide grade-appropriate brief education sessions on topics such as: What is cancer? What are its causes? And how does healthy eating and physical activity reduce risk?
7. Provide healthy snacks and improved physical activity in after-school programs.
8. Provide a greater choice of activities in physical education classes, including noncompetitive and lifelong activities, such as walking, aerobics, and swimming, and tailor activities to students' fitness level.



9. Ensure that school meals and snacks reflect the education students are receiving about nutrition and associated risk factors.
10. Support school health councils in the evaluation of school meals and policy initiatives.
11. Enforce school policies on access to and regulation of vending machines. Advocate for the availability of healthier options in school vending machines, such as 100% fruit juices, water, and fruits and vegetables, and encourage the use of alternative methods for fundraising.

Objective 3:

Increase access to a healthy diet and physical activity at Maryland workplaces.

Strategies:

1. Encourage employers to adopt health promotion programs and policies, including paid release time for physical activity during the workday, provision of on-site exercise facilities and activities, organization of workplace competitions such as stair climbing and running or walking teams, use of stairwell prompts, and gym membership subsidies.
2. Educate workplace events planners to offer healthy food and activity breaks during meetings and other events. Disseminate the American Cancer Society's "Meeting Well Tool."
3. Provide state tax incentives for employers to incorporate employee wellness programs.

Objective 4:

Increase the number of health care providers offering preventive nutrition and physical activity services.

Strategies:

1. Expand health care provider training regarding the connection among energy imbalance, suboptimal diet, alcohol intake, and cancer.
2. Establish and increase provider reimbursement for nutrition and physical activity counseling targeting high-risk patients within all payor systems in Maryland.
3. Create and establish guidance and assessment tools for use in all health care settings for the promotion of physical activity and healthy eating.
4. Educate providers about their importance as role models for patients, and provide incentives for them to adopt healthy diet and activity habits.

Objective 5:

Engage the public with appropriate health messages related to nutrition, obesity, physical activity, and cancer via the media.

Strategies:

1. Create or enhance local public service campaigns about the importance of healthy eating and physical activity in the prevention of cancer.
2. Create a news article series about nutrition, activity, and links to disease.
3. Pitch information about existing programs, campaigns, and specific events to news outlets in the hope of gaining media coverage.
4. Promote existing community, statewide, and national nutrition and/or physical fitness days to both local and statewide news outlets.

**Objective 6:**

Increase scientific knowledge regarding the relationship among nutrition, physical activity, and cancer.

Strategies:

1. Continue to encourage research on nutrition and physical activity in relation to cancer; continuously examine evidence in an effort to determine when evidence is strong enough to merit intervention.
2. Continue to encourage behavioral and economic research on targeted individual and societal interventions for suboptimal diet, obesity, and physical inactivity.
3. Educate the public about the need for etiologic research on nutrition, obesity, and physical activity and cancer.

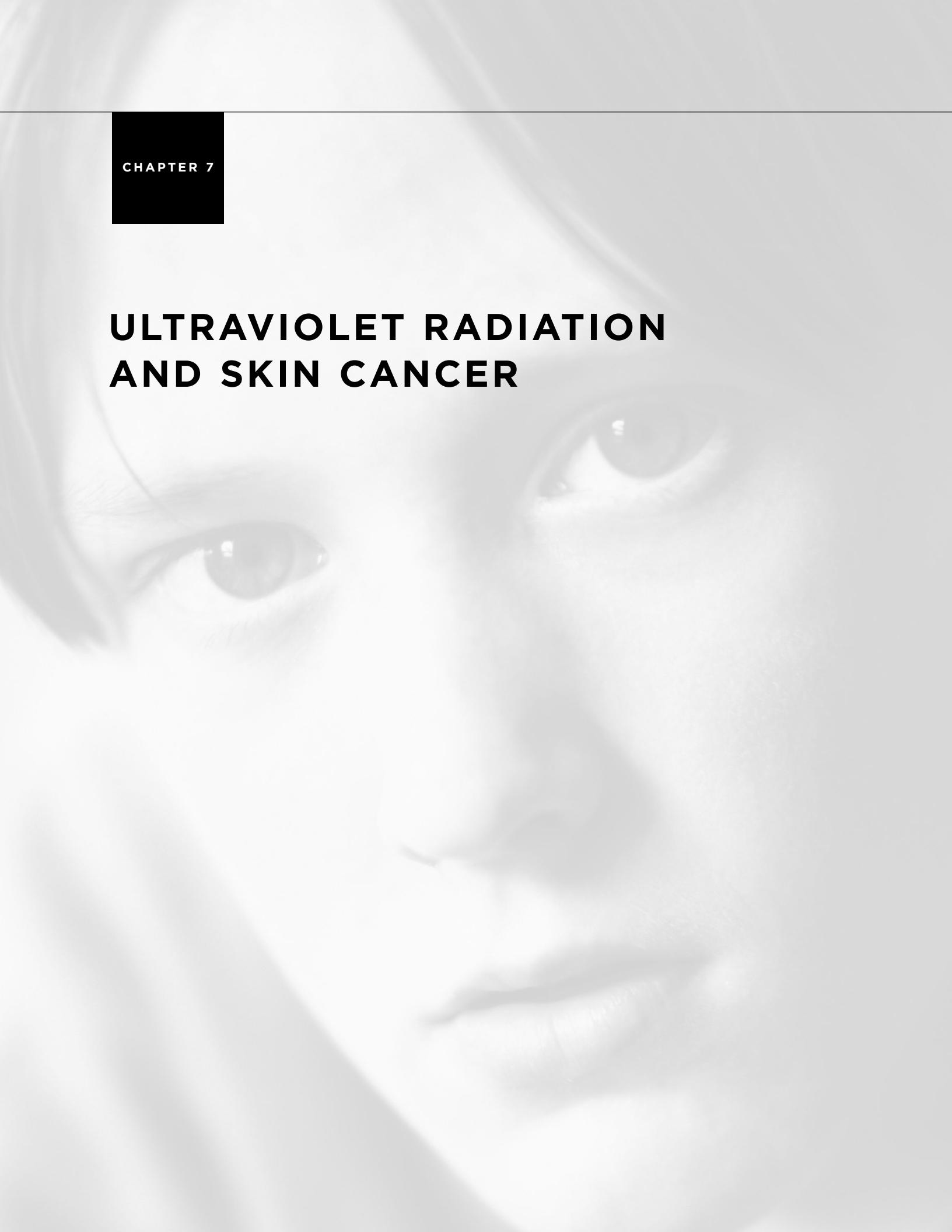
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CHAPTER 7

ULTRAVIOLET RADIATION AND SKIN CANCER



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ULTRAVIOLET RADIATION AND SKIN CANCER

Skin cancer is the most commonly occurring cancer in the United States, affecting some one million Americans and accounting for about 2% of all cancer deaths. The most serious form of skin cancer, melanoma, is expected to be diagnosed in 800 Marylanders in 2003.¹ Melanoma, while only accounting for 5% of all skin cancers, is the most deadly form of skin cancer and is responsible for 75% of all deaths from skin cancer.²

While skin cancer is generally associated with populations of advanced age, one in four people who develop melanoma are under the age of 40. It is now the most common cancer in women between the ages of 25 and 29.³ Cutaneous malignant melanoma is the most rapidly increasing cancer in whites⁴ and there has been a 50% increase in the death rate from it over 30 years (from 1969 to 1999). Most of that increase has been seen in men 65 and older, with rates in this group rising over 150%.⁵ The risk of melanoma is about 20 times higher for whites than for African Americans, because skin pigment has a protective effect.⁶ Melanoma develops in the cells of the skin that gives it color (melanocytes) and can spread to other parts of the body if diagnosed late. Survival depends upon the stage of the melanoma at diagnosis.

The three major types of skin cancer are basal cell carcinoma, squamous cell carcinoma, and melanoma. Basal cell carcinomas make up 75% of all skin cancers. Squamous cell carcinomas account for another 20% of all skin cancers. Basal and squamous cell carcinomas are both highly curable if treated early, but can cause considerable damage and disfigurement and occasionally death if treatment is delayed.

The major cause of skin cancer is unprotected exposure to ultraviolet radiation from the sun or tanning lamps in combination with genetic risk factors. Ultraviolet radiation (UVR) is commonly divided into three bands: UVA, UVB, and UVC. UVC is completely absorbed in the stratosphere before reaching the earth's surface. The rays of UVB are shorter and are the primary cause of tanning and sunburn. The longer rays of UVA penetrate the skin more deeply and contribute to wrinkling of the skin as well as tanning. Besides sunburn, skin cancer, and wrinkling, other negative effects of UVR include cataracts, macular degeneration, and immune system depression.⁷

Skin aging and cancer are delayed effects of sun exposure that don't typically emerge until many years after the exposure. Unfortunately, since the injury is not immediately visible, young people are often unaware of the damage caused by tanning. Physicians and scientists are especially concerned that cases of skin cancer will continue to increase as people who are tanning now in their teens and twenties reach middle age. Medical professionals agree that exposure to the sun's ultraviolet rays appears to be the most important factor in the development of skin cancer. In addition, disruption of the earth's ozone layer by pollution may cause rising levels of exposure to UVR. Nationally, the

rate of melanoma has been rising about 3% annually,⁸ although there is evidence that the rate is leveling off.

Risk Factors

Certain risk factors may increase the chance of developing skin cancer. The most significant risk factors for skin cancer are:

Exposure to UVR and Sunburn

Nearly all skin cancers occur in fair-skinned individuals who have been exposed to the sun, X-rays, or ultraviolet light for prolonged periods.⁹ It is thought that chronic, long-term exposure to UVR is the cause of squamous cell carcinomas.¹⁰ This type of cancer frequently occurs in an older population and in areas of the body exposed to the sun, such as the face, arms, and ears. The mechanism for development of basal cell carcinoma is more complex and may involve a combination of chronic and intermittent exposure patterns.¹¹ The relationship between UVR exposure and melanoma has not been clearly defined. Some studies have implicated intermittent sun exposure, which typically occurs on areas of the skin not exposed to the sun regularly.^{12,13} Severe sunburns in childhood and adolescence may be particularly important in the development of melanoma.¹⁴ However, other studies have indicated that sunscreen, which protects against sunburn, may not protect against UVR-associated melanoma.¹⁵ In addition to the risks associated with sun exposure, increased risk of developing skin cancer has been observed in patients treated with psoralen-UV-A (PUVA) therapy, which has been widely used to treat psoriasis and other cutaneous diseases.^{16,17}

Nevi (Moles)

The presence of large numbers of atypical moles increases the risk of melanoma. Individuals with certain types of pigmented lesions (dysplastic or atypical nevus), several large nondysplastic nevi, many small nevi, or moderate freckling have a twofold to threefold risk of developing melanoma. Individuals with familial dysplastic nevus syndrome or with several dysplastic or atypical nevi are at high risk of developing melanoma.¹⁸

Fair Skin, freckling, and light hair

Melanoma risk is about 20 times higher for whites than for African Americans. Whites with red or blond hair and fair skin that freckles or burns easily are at especially high risk of developing melanoma.¹⁹ While melanoma is more prevalent in whites than in blacks, those with darker skin types are not immune.²⁰ In

blacks, melanoma is most commonly found in lighter pigmented areas such as the palms, soles of the feet, and under the nails.

Family history

Risk of melanoma is greater if one or more of a person's first-degree relatives have been diagnosed with melanoma.²¹

Personal history

Persons with non-melanoma skin cancer are at higher risk for developing additional skin cancers.²²

Immune suppression

Patients who have been treated with immune suppressants have an increased risk of developing melanoma.²³

Age

About half of all melanomas occur in people over the age of 50. However, melanoma is one of the most common cancers in people under 30; melanoma that runs in families often occurs at a younger age.²⁴

Xeroderma pigmentosum (XP)

XP is a rare, inherited condition that causes people to be less able to repair DNA damage caused by sunlight and thus have a higher risk for developing melanoma, basal cell carcinoma, and squamous cell carcinoma.²⁵

Burden of Melanoma in Maryland

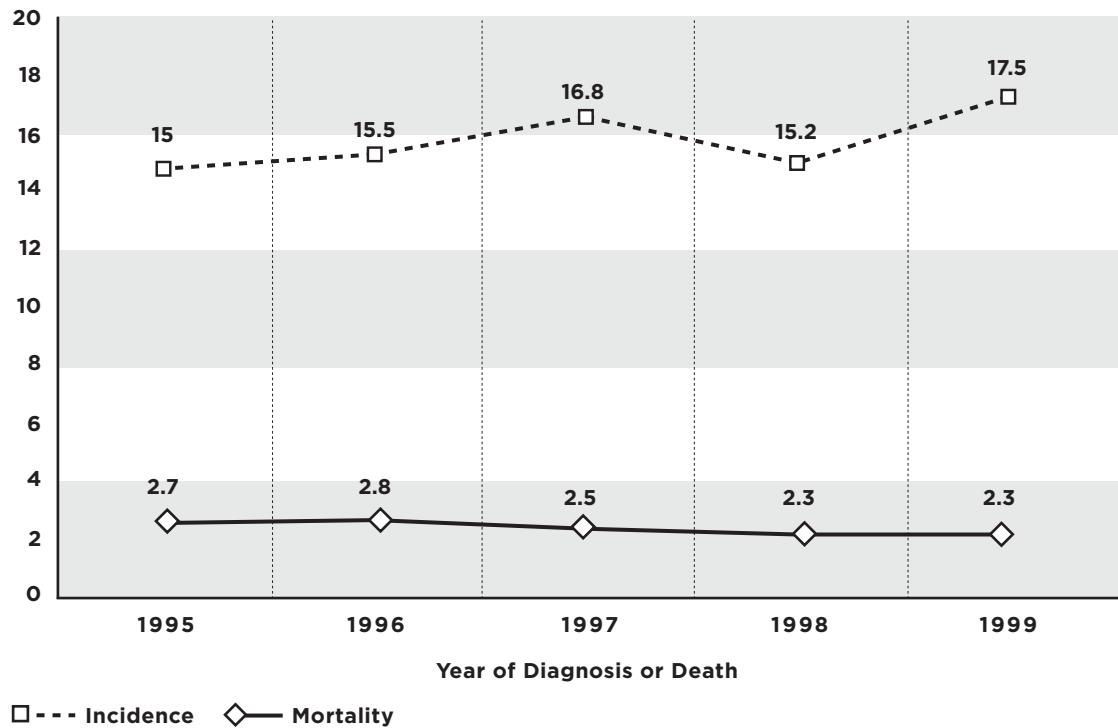
From 1995 to 1999, melanoma incidence rates in Maryland increased an average of 3.9% per year.²⁶ Conversely, melanoma mortality rates in Maryland have been falling during the same time period, dropping an average of 4.2% per year (Figure 7.1).²⁷ Maryland is ranked 42nd for melanoma mortality among the states and the District of Columbia.²⁸

A total of 884 persons in Maryland were diagnosed with melanoma in 1999. In the same year, 112 people died of melanoma in Maryland. Maryland melanoma incidence and mortality rates are similar to national melanoma rates. In 1999, the incidence rate for melanoma in Maryland was 17.5 per 100,000 population, which is very close to the national rate of 17.4 per 100,000 population. Also in 1999, the Maryland mortality rate was 2.3 per 100,000 population, similar to the national rate of 2.7 per 100,000 (Table 7.1).

Melanoma incidence increases with age and Maryland's

Figure 7.1

**Melanoma Cancer Incidence and Mortality by Year of Diagnosis and Death
in Maryland, 1995-1999**



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; Maryland Division of Health Statistics, 1995-1999.

Table 7.1

**Melanoma Cancer Incidence and Mortality Rates by Sex and Race
in Maryland and the United States, 1999**

Incidence 1999	Total	Males	Females	Whites	Blacks
New Cases (#)	884	487	397	858	16
MD Incidence Rate	17.5	22.1	14.5	23.3	**
U.S. SEER Rate	17.4	21.7	14.2	20.1	1.2
Mortality 1999	Total	Males	Females	Whites	Blacks
MD Deaths (#)	112	67	45	5	<6
MD Mortality Rate	2.3	3.3	1.7	3.0	**
U.S. Mortality Rate	2.7	3.8	1.8	3.0	0.4

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Cells with five or fewer non-zero cases are not presented per DHMH/MCR Data Use Policy.
**Rates based on cells with 25 or fewer non-zero cases are not presented per DHMH/MCR Data Use Policy.
S=Suppressed to ensure confidentiality of cell in other column.
Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

age-specific incidence rates mirror those in the U.S. (Figure 7.2). Melanoma incidence is much higher among males than females in both the U.S. and Maryland (Figure 7.3). In addition, melanoma mortality rates for Maryland males are much higher than for females. In 1999, the melanoma mortality rate was nearly twice as high for males than for females in Maryland.²⁹

The American Joint Committee on Cancer (AJCC) TMN Staging System is used most often to describe the extent of melanoma. In this system, melanoma is given a T category (primary tumor thickness), an N category (number of involved regional nodes), and an M category (presence of metastasis). Patients are assigned a stage (I–IV) based on the TMN values. Stage I and II indicate primary tumors of increasing thickness, stage III indicates regional lymph node involvement, and stage IV indicates metastatic disease. This staging system divides patients into clinically meaningful prognostic groups.

Based on SEER data for the time period 1992–1997, 82% of all melanoma cancer cases in the U.S. during these years were diagnosed at the local stage, when the cancer is confined, and had not reached the lymphatic system (Figure 7.4). In contrast, only 54.6% of melanoma cases in Maryland were diagnosed at the local stage, when there is a higher chance of survival. However, this proportion may be underrepresented due to the high percent of unstaged melanoma cases in Maryland.³⁰

Survival rates are not available for Maryland diagnoses from the Maryland Cancer Registry, but in the United States, five-year relative survival rates for melanoma have been steadily increasing for whites since 1974, growing from approximately 80% to 90% between 1974 and 1997 (Figure 7.5). Survival rates for blacks in the U.S. have not experienced the same trend. Five-year survival rates of blacks fluctuated between 1974 and 1997, ultimately decreasing from approximately 68% in 1974 to 60% in 1997.

Disparities

- Blacks have lower five-year survival rates than whites after diagnosis of melanoma (U.S. data only).
- The melanoma mortality rate for Maryland males is nearly twice as high than for females.
- The Eastern Shore and Northwest regions in

Maryland have higher incidence rates of melanoma than other regions of Maryland and the U.S. This disparity may be attributable to increased exposure to UVR seen in occupations common in these regions such as watermen and farmers.

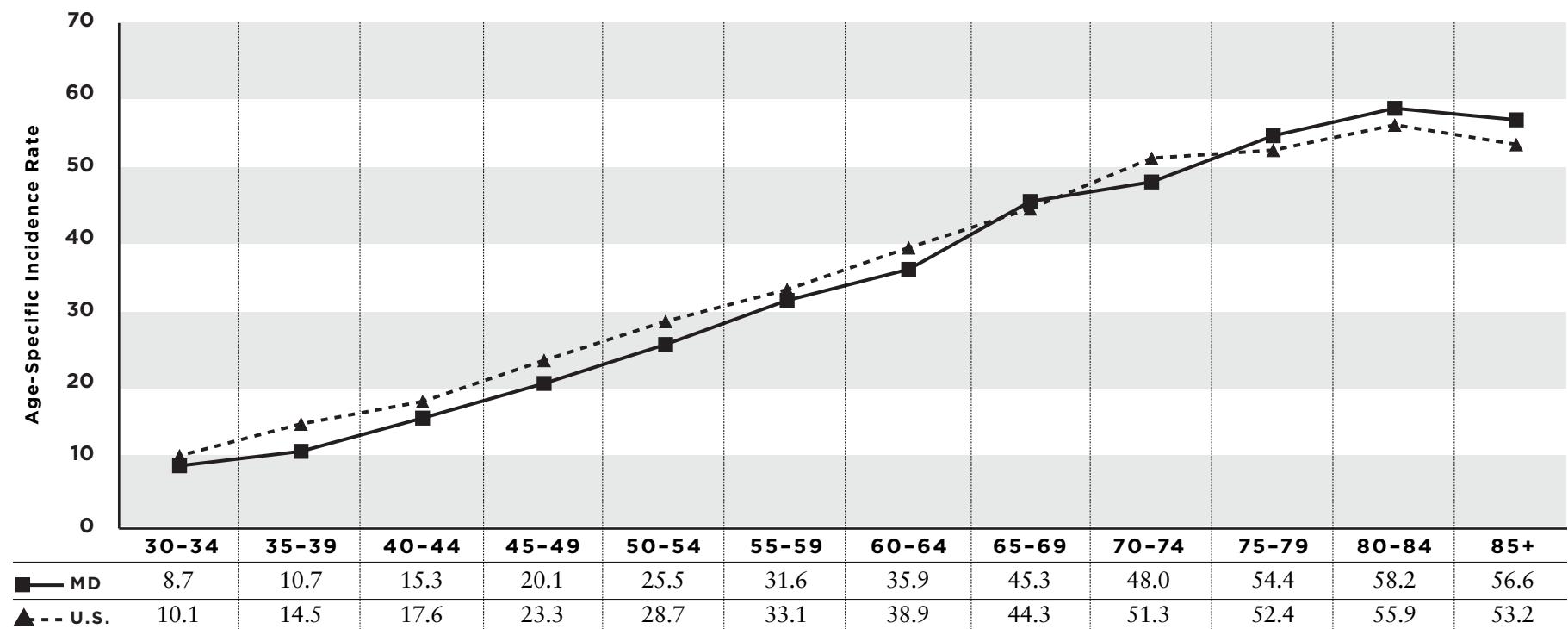
Prevalence of Sun-Safe Behaviors in Maryland

There is considerable room for improvement for Marylanders to adopt behaviors to protect themselves from the harmful effects of UVR. Unless otherwise stated, statistics regarding sun-safe behaviors among Marylanders are from the Maryland Behavioral Risk Factor Surveillance System.³¹ In 1998, 59% of adults used at least one of the following measures to protect themselves from UVR: avoiding the sun between 10:00 a.m. and 4:00 p.m., wearing sun-protective clothing, or wearing sunscreen. However, 45.6% of adults reported that they never use sunscreen with an SPF of 15 or higher when outdoors for an hour or more (Figure 7.6). In 1999, 37.3% of adults reported having a severe sunburn before the age of 18. These factors combined illustrate the inconsistency of sun-safe practices by Maryland adults.

Unfortunately, inconsistency in sun-safe behaviors among Maryland adults appears to be translating to somewhat low rates of sun-safe practices for Maryland children. In 1998, only 41.4% of adults reported always taking measures to protect their child's skin from UVR when the child is outdoors on a sunny day for an hour or more (Figure 7.7). In two years, this percentage only increased slightly, to 42.1%. In addition, a 1999 survey of 2,775 Maryland adolescents demonstrated a low level of knowledge about skin cancer prevention and less than optimal sun-safety behaviors. The study concluded that favorable attitudes toward sun protection should be nurtured, as they were found to correlate with positive behaviors.³²

Primary Prevention

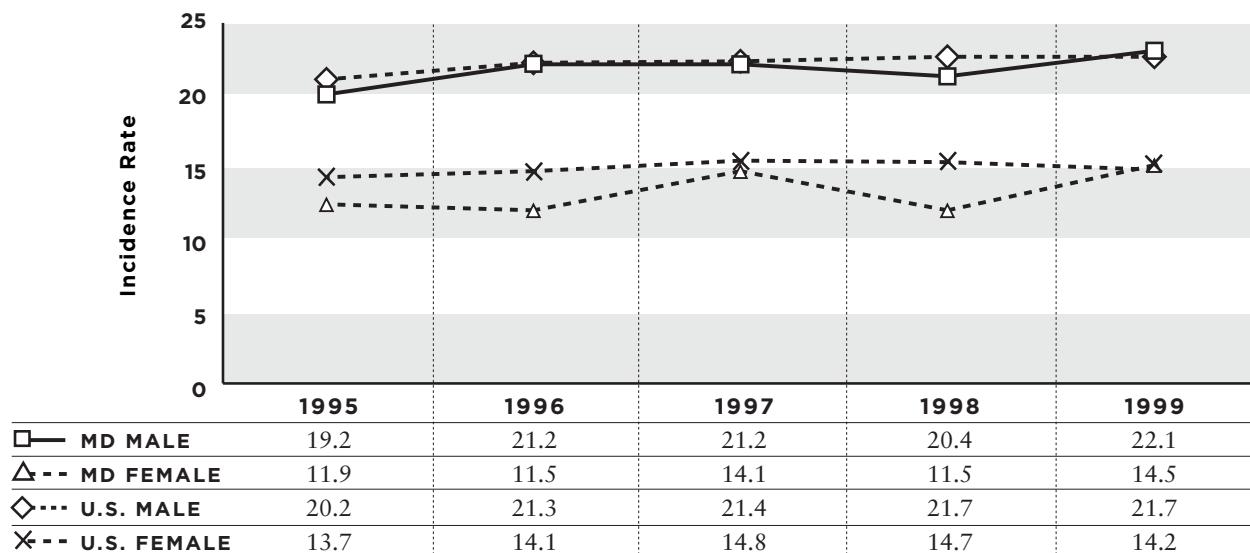
Given the role of sun exposure in the development of many skin cancers including melanoma, sun avoidance and sun protection are strongly recommended by the American Academy of Dermatology³³ and the American Cancer Society.³⁴ In addition, the National Cancer Institute states that the avoidance of sunburns, especially in childhood and adolescence, may reduce the incidence of cutaneous melanoma.³⁵

Figure 7.2**Melanoma Cancer Age-Specific Incidence Rates in Maryland and the United States, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 population.

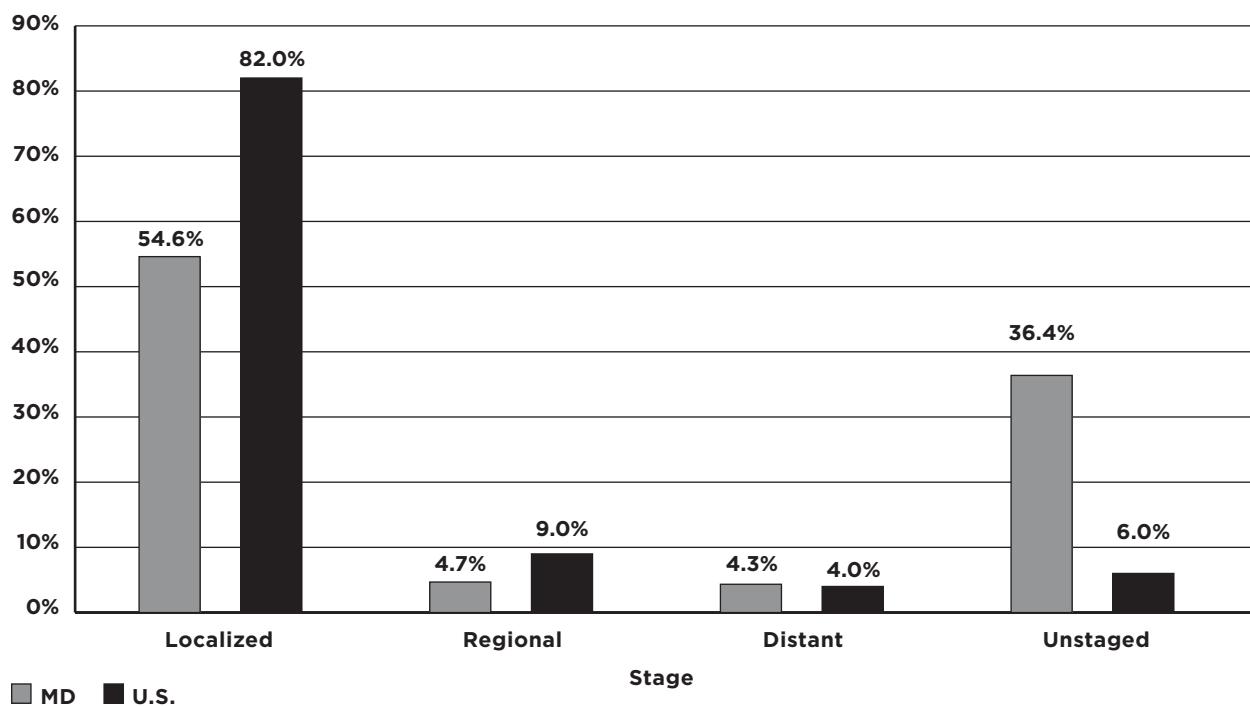
Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 7.3
Melanoma Cancer Incidence by Sex in Maryland and the United States, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; Maryland Division of Health Statistics, 1995-1999.

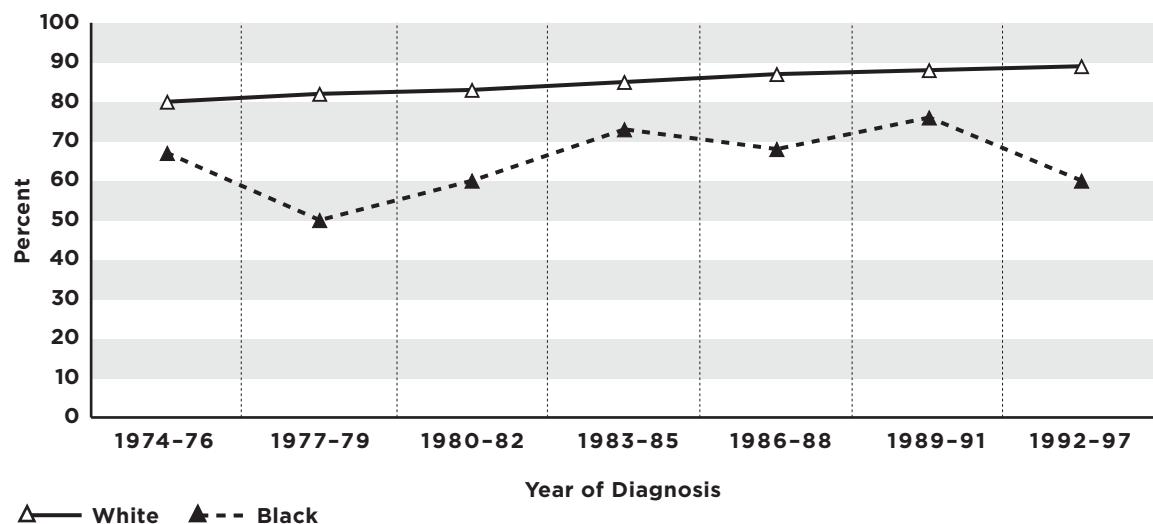
Figure 7.4
**Melanoma Cancer Distribution by Stage at Diagnosis
in Maryland and the United States, 1992-1997**



Source: Maryland Cancer Registry, 1992-1997; SEER, National Cancer Institute, 1992-1997.

Figure 7.5

**Five-Year Relative Survival Rates Following Diagnosis for Melanoma Cancer
in the United States, by Race, 1974-1997**



Source: SEER, National Cancer Institute, 1974-1997.

Education and Public Policy

Educational efforts and policy changes are vital for the successful prevention of skin cancer among Marylanders. At a minimum, educational efforts directed toward the general public should include sun-safety information including the importance of wearing sun-protective clothing, the use of sunscreen, avoidance of sun exposure from the hours of 10:00 a.m. to 4:00 p.m., the use of shade structures, and the avoidance of artificial tanning sources. In addition, advice regarding sunscreen should include: (1) use sunscreen with SPF 15 or higher, (2) apply it 20 minutes prior to exposure, (3) use 1 ounce of sunscreen per application, and (4) reapply sunscreen every two hours or after swimming or excessive sweating.

Several population groups warrant special consideration for educational efforts. Persons in occupations that require them to work outdoors should be encouraged to take special precautions and practice sun-safety behavior to protect themselves from skin cancer. In addition, persons who routinely see the skin of their clients, such as barbers, hairdressers, cosmetologists, manicurists, and massage therapists, may provide a nontraditional avenue for skin cancer awareness. Educating these non-traditional service providers about the signs of skin cancer would enhance community awareness of skin cancer and promote sun-safe behaviors.

Given the link of sunburn (particularly before the age

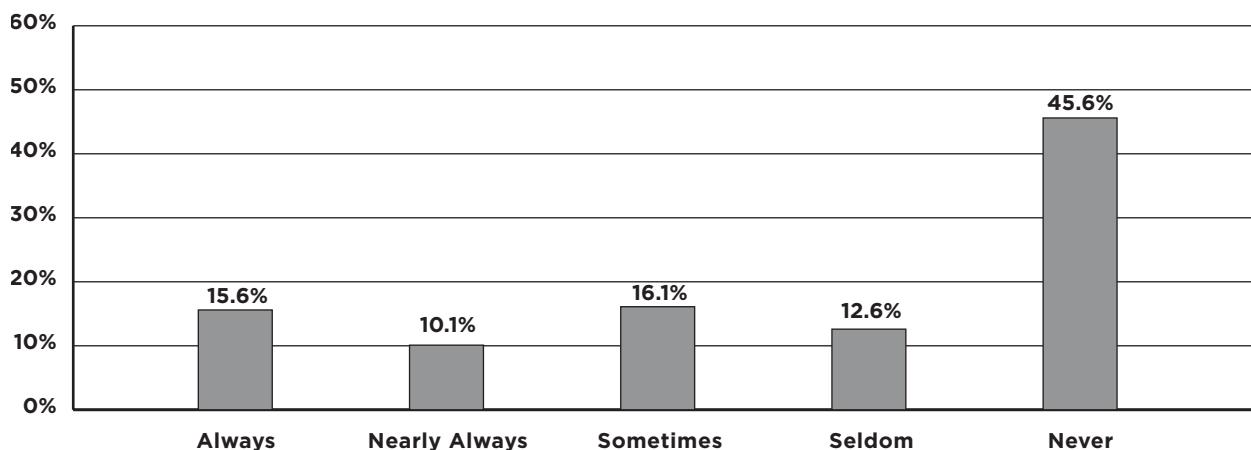
of 18) to melanoma and other skin cancers, there is a significant need to target children and youth with interventions designed to increase their sun-safe behaviors and prevent damaging sun exposure. Because schools are a primary source of information for children and adolescents, educators can play a critical role in providing students with valuable messages in the classroom on proper sun-safe behaviors and the damaging effects of UVR. Schools may also make an impact by providing shade structures for students during outdoor playtime or physical education. Of course, funding is required for schools to ensure that proper shade structures are in place.

In 2001, the Maryland State Department of Education (MSDE) developed “Guidelines for Protecting Students and Staff from Overexposure to the Sun.”³⁶ These guidelines encourage and provide resources for school health services supervisors to perform a school environment assessment and develop sun-safety policies for their schools. The guidelines specifically indicate that sunscreen is not considered a medication and that students should be allowed to use sunscreen brought to school. These guidelines serve as a standard of care for school nurses and are not recorded in Maryland statutory law.

In 2002, the Centers for Disease Control and Prevention (CDC) published guidelines that included seven broad strategies that school programs can use to reduce the risk for skin cancer among students:³⁷

Figure 7.6

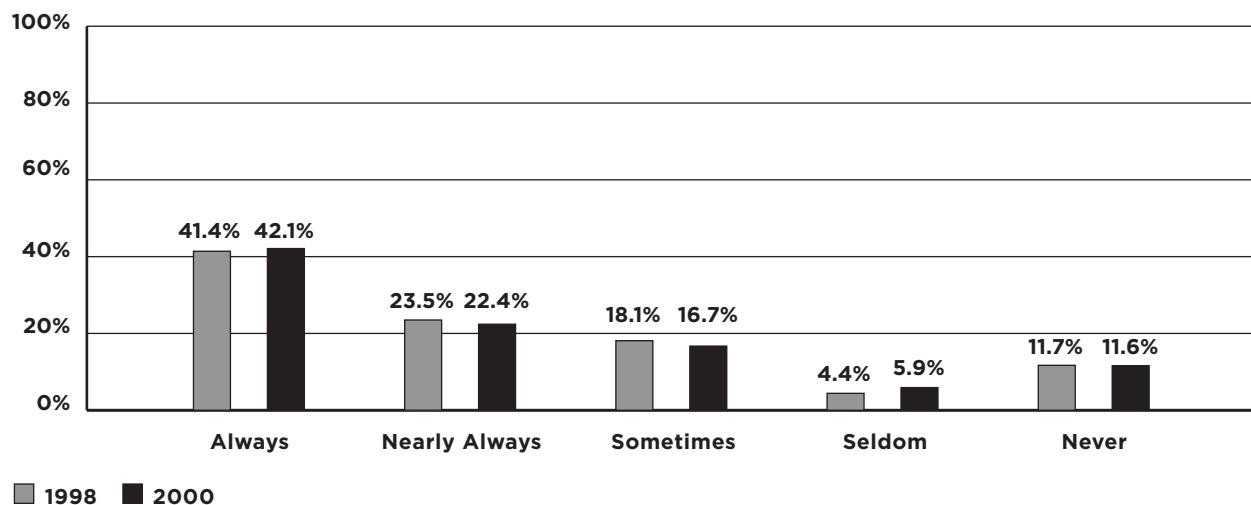
**Maryland Adults Who Use Sunscreen with a Rating of 15 or Higher
When Outdoors for an Hour or More, 1998**



Percentages reflect weighted values.
Source: Maryland BRFSS.

Figure 7.7

**When the Youngest Child Under Age 13 is Outdoors on a Sunny Day for an Hour or More,
How Often is His or Her Skin Protected From the Sun? 1998, 2000**



■ 1998 ■ 2000

Percentages reflect weighted values.
Source: Maryland BRFSS.

- Establish policies that reduce exposure to UV radiation.
- Provide and maintain physical and social environments that support sun safety and that are consistent with the development of other healthful habits.
- Provide health education to teach students the knowledge, attitudes, and behavioral skills they need to prevent skin cancer. The education should be age-appropriate and linked to opportunities for practicing sun-safety behaviors.
- Involve family members in skin cancer prevention efforts.
- Include skin cancer prevention knowledge and skills in preservice and inservice education for school administrators, teachers, physical education teachers, coaches, school nurses, and others who work with students.
- Complement and support skin cancer prevention education and sun-safety environments and policies with school health services.
- Periodically evaluate whether schools are implementing the guidelines on policies, environmental change, education, families, professional development, and health services.

Both the MSDE and CDC guidelines are referenced in a joint resolution on skin cancer prevention signed by the Maryland State Superintendent of Schools and representatives from several other organizations in May 2003.

Continued promotion of these guidelines among school officials is necessary, as is representation of skin cancer awareness and sun-safety behavior in the health curricula of Maryland schools. In addition, state policy changes may be needed to further provide for sun-safety practices among Maryland schoolchildren. Several states, including California and Hawaii, have enacted legislation regarding sun-safety practices in schools. California law SB 310 provides pupils with the right to wear protective articles of sun-protective clothing while outdoors, including, but not limited to, hats. California law SB 1632 allows pupils to use sunscreen during the school day.

In addition to school-based education and policies, youth organizations such as the Girl Scouts, Boy Scouts, 4H, and other sports and recreation organizations should also be targeted for skin cancer awareness and education about sun safety. Day-care centers and

preschools should strive to implement sun-safe programs and policies as well.

Artificial UVR and Tanning Booths

Teenagers in particular should be educated on the importance of skin cancer awareness and sun-safety behaviors. The tanning salon industry has made considerable marketing efforts targeting teenagers, boasting that tanning beds may be used as a safe alternative to sun exposure. These claims are false; exposure to tanning lamps, booths, and stands is even more dangerous than being out in the sun. UVA and UVB exposure from tanning machines is more concentrated and is not a safe alternative to sun exposure. Regulations should be enacted in Maryland to restrict youth access to tanning salons.

In 2002, the state of Texas enacted statute HB 663, a bill that should be used as a model in Maryland for regulating tanning facilities. Texas law HB 663 states that tanning facilities shall give each customer a written statement warning of the dangers of using the tanning device that will include notice that usage increases the risks for skin cancer, in addition to skin burns and premature aging (HB 663, section 145.005a). The statute also calls for a sign with warning statements about ultraviolet radiation and the possible effects (HB 663, section 145.006a) to be placed at each tanning device in a conspicuous location. The law also specifies certain age restrictions. Youth ages 13 and younger are not allowed to use the tanning devices unless under the direction and written permission of a physician and the parent/guardian must remain at the facility during time of usage; youth aged 14 and 15 must be accompanied by a parent/guardian who must remain at the tanning facility during the tanning session; and youth aged 16 and 17 must have a written informed consent statement signed and dated by the person's parent or guardian stating that they have read and understood the warnings given by the tanning facility.

Screening for Skin Cancer

A noninvasive visual inspection of the skin for skin cancer can be performed by patients or by health care providers. The American Academy of Dermatology (AAD) recommends regular skin self-examination and provides instructions for a thorough self-exam.³⁸ If there are any changes in the size, color, shape, or tex-

ture of a mole, the development of a new mole, or any other unusual skin changes, the AAD recommends that people see a physician immediately.

Patient self-exams, however, are not a substitute for yearly skin exams by a dermatologist. In one study, melanomas detected by physicians were significantly thinner than those detected either by a patient or by a patient's spouse.³⁹ A recent publication on results of the AAD skin cancer screening programs from 1985 to 1999 found that nearly 30% of screened subjects had a skin lesion noted that was suspicious for a skin cancer or pre-cancer.⁴⁰ In addition, melanomas that were biopsied as a result of the skin cancer screening had a greater likelihood of being less than 1.50 mm in thickness as compared with population-based registries.⁴¹ The Skin Cancer Foundation recommends monthly skin self-exams and yearly skin screening by a dermatologist. The American Cancer Society recommends a yearly cancer-related checkup, which should include examination of the skin and counseling regarding signs and symptoms of skin cancer.⁴²

Despite these findings and guidelines, several national organizations do not recommend routine skin screening by health care providers for the early detection of melanoma. The U.S. Preventive Services Task Force concluded that "the evidence is insufficient to recommend for or against routine screening for skin cancer using a total-body skin examination for the early detection of cutaneous melanoma, basal cell cancer, or squamous cell skin cancer."⁴³ In addition, the National Cancer Institute indicates that "there is insufficient evidence to establish whether a decrease in mortality occurs with routine examination of the skin. There is also insufficient evidence to establish whether other theoretical benefits (such as decreased morbidity from less aggressive treatments) or harms associated with incorrect diagnosis occur."⁴⁴ However, the National Cancer Institute also reports that several observational studies have provided some evidence that screening for skin cancer may be effective. "For example, an educational campaign in Western Scotland, promoting awareness of the signs of suspicious skin lesions and encouraging early self-referral, has been reported. There was a decrease in mortality rates associated with the campaign. No randomized controlled trials have been performed, however, to assess screening efficacy. A case-control study of skin self-examination by 650 cases (and 549 controls) diagnosed in Connecticut has been reported. The intervention was associated with reduced melanoma incidence, and the authors estimat-

ed that monthly skin self-examination might decrease disease-specific mortality by 63%. It has been suggested, however, that the observed incidence effects may have been the result of study biases, which frequently affect case-control study designs."⁴⁵

Despite this lack of evidence, the UVR and Skin Cancer Committee encourages health care providers, especially primary care physicians, to perform routine skin exams and educate patients on skin self-exams. In addition, health insurers should be encouraged to adequately reimburse dermatologists and other health care providers for time-consuming full-skin exams.

Provider Education

Because thin melanomas have a greater than 95% survival rate, physician education and awareness regarding skin cancer detection is a key factor in patient survival. Currently, many physicians do not receive sufficient education on skin cancer screening to feel competent in this area. A survey conducted at the Boston University School of Medicine found that in 1996 and 1997, 52% of fourth-year students rated themselves as unskilled in skin cancer examinations.⁴⁶ Another study evaluated readiness of primary care physicians to triage suspicious skin lesions. In this study, 50% of primary care residents failed to diagnose correctly nonmelanoma skin cancer and malignant melanoma.⁴⁷ This deficit of skin cancer knowledge was also apparent in a survey of family practitioners; more than 50% of those surveyed stated that they lacked the confidence to recognize melanoma.⁴⁸

Skin cancer screening and education occur at a lower rate in primary care physicians' offices than other types of cancer education or screening. A retrospective database study, utilizing the National Ambulatory Medical Care Survey from 1997, found skin examination was reported in 15.8% of all primary care office visits and skin cancer education and counseling occurred during only 2.3% of visits.⁴⁹ In another survey, 52% of family physicians and internists rated skin cancer screening as "extremely important," but only 37% reported performing total body skin exams on 81% to 100% of patients.⁵⁰

Educational interventions and curriculum enhancement for physicians and medical students can be effective. A two-hour multifaceted educational intervention on skin cancer control has been designed for primary care providers. This curriculum resulted in significant increases in provider skin cancer control practices and

attitude toward total-body skin examination.⁵¹

Dermatologist Availability

The state of Maryland has 263 licensed dermatologists. Availability of dermatology appointments is variable depending on geographic location. Areas that may be considered underserved include western Maryland, southern Maryland, Harford County, and the Eastern Shore. Methods to increase access to dermatologists in these areas should be developed.

Diagnosis of dermatologic conditions using telemedicine has been found to be an acceptable means for diagnosing skin conditions. Telemedicine can be defined as the practice of medicine remotely, primarily by exchanging images, sometimes accompanied by text and audio, over a communications network.⁵² Complete agreement was obtained on 78% of dermatologic telemedicine diagnoses versus local evaluations in a study evaluating 68 dermatological conditions. Partial agreement was reached on another 21% of evaluations.⁵³

Current Efforts in Maryland

There are several community and governmental organizations in Maryland that are involved in educating the public and providing programs in skin cancer prevention and sun-safety behavior. These organizations are involved in public education programs, provide school curricula, offer additional resources via websites and other materials, and provide local assistance with policy changes.

Coalition for Skin Cancer Prevention in Maryland

The Coalition for Skin Cancer Prevention in Maryland is a collaborative effort to raise awareness about the importance of skin cancer prevention and to provide sun-safety information, resources, and support statewide. The coalition is in its sixth year, having been established in 1997 through a grant from the U.S. Centers for Disease Control and Prevention (CDC). As of March 2001, the coalition is funded by a grant from the Maryland Department of Health & Mental Hygiene. The coalition is comprised of concerned citizens and representatives from forty organizations, including state and local governmental agencies, not-for-profit organizations, for-profit companies, and professional medical societies.

The coalition has designed “SunGuard Your Skin,” a two-lesson middle school curriculum, taught to over 30,000 students in more than 100 public and private schools in the state. The program, consisting of a teacher’s guide, student booklet, parent letter, and video, has demonstrated significant positive changes in knowledge, attitudes, and behaviors. The SunGuard Your Skin program is available to educators free of charge on their website, SunGuardMan Online, <http://www.sunguardman.org>. SunGuardMan Online is a multi-media, interactive experience for both children and adults, which contains games, contests, activities, and the four-episode cartoon, *The Adventures of SunGuard Man*. In addition, the website offers information about the dangers of ultraviolet radiation, types of skin cancer, risk factors for skin cancer, protective measures, and how to perform a skin self-exam, along with links to many related sites.

The coalition’s mascot, SunGuard Man, appears in a variety of venues to disseminate the coalition’s skin cancer prevention message to children and adults. There are currently five SunGuard Man costumes placed with coalition member organizations throughout the state. The coalition has adopted the American Cancer Society’s Sun Safe Community program, which is a five-channel approach to skin cancer prevention. Through this model, the coalition is working with schools, child-care centers, parks and recreation areas, primary care physicians’ offices, and the media to bring its sun-safety message to all Marylanders. Every year, on Melanoma Monday, the coalition holds a press conference, during which a governor’s proclamation is read, declaring the month of May Skin Cancer Prevention and Detection Month in Maryland. At this event prizes are awarded to winners of the coalition’s annual, statewide “SunGuard Your Skin” poster contest.

American Cancer Society

The American Cancer Society (ACS) is involved in providing public education on all aspects of early detection and prevention of cancer. In addition to providing educational programs and presentations and materials to local communities, ACS has designed a multi-channel program that targets children aged 18 and younger with skin cancer prevention and sun-safety education. “Sun Safe Community” is a program in which schools, day care centers, media, primary care providers, and parks and recreation programs come together to educate parents and children in their community. Community members, health organizations, governmental officials, and media representatives have

formed committees to design a local plan and work together to make their community a “Sun Safe Community.” The program includes a pre-school curriculum with songs, activities, and lessons; media releases and public service announcements; a primary care office manual; and informational materials and posters. Since 2001, the Sun Safe Community has been implemented in four counties in Maryland and has been successful in promoting skin cancer prevention education, sun-safety behaviors, and in some cases, policy changes in schools, day care centers and preschools, and recreational areas.

Environmental Protection Agency

The U.S. Environmental Protection Agency has designed an education program for schools that targets children in grades K–8. The SunWise School Program designs activities and materials to be used by teachers and administrators to better educate students in skin cancer prevention and sun safety behaviors. The Tool Kit contains cross-curricular classroom activities for grades K–2, 3–5, and 6–8. Materials, storybooks, comic books, and activity books reinforce the sun-safety lessons. The SunWise School Tool Kit is available through the EPA’s website (<http://www.epa.gov/sunwise/>) and is available at no cost to interested schools. The EPA’s website also includes information for parents and has a variety of games and activities for children. Storybooks and an activity book are also available on the website.

Ulman Cancer Fund for Young Adults

The Ulman Cancer Fund for Young Adults provides support services, local cancer resource information, and assistance to young adults, families, and others affected by cancer. The Ulman Fund also promotes skin cancer awareness and prevention education through local programs and their website (<http://www.ulmanfund.org>).

There are many other national and governmental organizations that promote and support skin cancer awareness and sun-safety education such as the American Academy of Dermatology, the National Cancer Institute, and the National Institutes of Health.

Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁵⁴ related to skin cancer:

Objective:

Reduce the rate of melanoma cancer deaths to 2.5 deaths per 100,000 population.

The U.S. baseline was 2.8 melanoma cancer deaths per 100,000 population in 1998 (age-adjusted to the year 2000 standard population).

Objective:

Increase the proportion of persons who use at least one of the following protective measures that may reduce the risk of skin cancer to 75%: avoid the sun between 10 a.m. and 4 p.m., wear sun-protective clothing when exposed to sunlight, use sunscreen with a sun-protective factor (SPF) of 15 or higher, and avoid artificial sources of ultraviolet light.

The U.S. baseline was 47% of adults aged 18 years and older regularly used at least one protective measure in 1998.



Ultraviolet Radiation and Skin Cancer Goals, Objectives, and Strategies

Goals:

Prevent increases in mortality from melanoma cancer.

Increase utilization of sun-safe behaviors.

Targets for Change

By 2008, maintain the mortality rate from melanoma of the skin at a rate of no more than 2.7 per 100,000 persons in Maryland.

The Maryland baseline was 2.7 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Division of Health Statistics.

By 2008, increase the percent of Maryland adults to 71% who use at least one of the following sun protective measures: avoid sun from 10am–4pm, wear sun protective clothing, or wear sunscreen.

The Maryland baseline was 59% in 1998.

Source: BRFSS.

Objective 1:

Increase public awareness about sun safety and skin cancer.

Strategies:

1. Formulate and disseminate an appropriate educational message for the general public about melanoma and skin cancer prevention. The message should include a recommendation about sun-safe behaviors including:
 - proper use of a sunscreen that is SPF 15 or higher, including the need for 1 ounce per application, application 20 minutes before exposure, and reapplication every 2 hours or after swimming or excessive sweating.
 - avoidance of the sun during peak hours and wearing protective clothing, hats, and sunglasses.
 - avoidance of artificial UV light sources such as tanning beds.
2. Form partnerships with youth service providers and organizations, including preschools, child care providers and facilities, Girl Scouts, Boy Scouts, 4H, and other youth recreation and sports organizations.
3. Form partnerships with occupational organizations to address sun-safety behavior and skin cancer awareness among persons whose occupations require them to work outdoors.
4. Form partnerships with organizations and individuals who routinely see and care for their clients' skin (such as barbers, hairdressers, cosmetologists, manicurists, and massage therapists) to promote non-traditional avenues for sun safety and skin cancer education.



5. Inform the general public about the Maryland State Department of Education Guidelines that:
 - allow use of sunscreen by students.
 - state that sunscreen is not considered a medication and therefore students may keep it with them during the day.
 - advocate use of sun-safe clothing, including the use of wide-brimmed hats (for all ages).
 - advocate placement of play equipment in shaded areas when possible.
 - recommend use of safety sunglasses that provide 100% protection from the sun (for all ages).

Objective 2:

Increase physician awareness about sun safety and skin cancer.

Strategies:

1. Increase educational opportunities for health care providers, especially pediatricians, regarding the need for skin cancer prevention and early detection.
2. Develop CME programs to teach skin cancer recognition and how to educate patients about skin self-exams and sun protection.
3. Educate health care providers that melanoma may occur in African Americans, particularly on the palms, soles of feet, and under nails.
4. Encourage health care providers to perform skin exams during each routine physical exam.
5. Develop a Medical Advisory Committee and Minimal Clinical Elements guidelines to address melanoma in local public health programs.
6. Explore the possibility of using telemedicine to supplement the low availability of dermatologists within rural and underserved areas.
7. Encourage dermatologists to participate in annual public skin screenings.
8. Develop and fund a pilot program including the development of a medical school curriculum component such as “How to perform a skin cancer screening exam and what to look for.”
9. Encourage health insurers to adequately reimburse health care providers for full skin exams.

**Objective 3:**

Increase the number of melanoma cancers diagnosed at an early stage.

Strategies:

1. Increase performance of skin exams during routine physical exams.
2. Educate the public about the need for regular skin self-exams.

Objective 4:

Develop improved data to document the prevalence of skin cancer examinations and appropriate diagnosis and follow-up of melanoma and other skin cancers in Maryland.

Strategies:

1. Increase data collection relating to basal and squamous cell skin cancers and melanoma in Maryland.
2. Implement steps to document survival rates for melanoma and skin cancers in Maryland.
3. Improve reporting of diagnostic results to the Maryland Cancer Registry to reduce the number of unstaged cases of melanoma in Maryland.
4. Expand data collection related to skin cancer prevention and screening practices.

Objective 5:

Implement policy changes to increase the use of sun-safe behaviors, particularly among youth in Maryland.

Strategies:

1. Model legislation in Maryland based on Texas law HB 663 which requires the posting of warning signs in tanning salons, and regulates their use by those under the age of 18, as follows:
 - children under the age of 13—not allowed to use unless prescribed by physician.
 - children age 13 to 15—must be accompanied by parent/guardian.
 - children age 16 and 17—written consent by parent/guardian is required.
2. Explore the need for policy changes to allow for the use of sun-protective clothing, including hats, by students while at school.
3. Provide funding for provision of shade structures at Maryland schools and other facilities serving youth organizations.

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CHAPTER 8

ENVIRONMENTAL ISSUES AND CANCER

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ENVIRONMENTAL ISSUES AND CANCER

The prevailing model of carcinogenesis holds that cancer cells arise from the accumulation of many small alterations in the DNA of normal cells. These alterations, or mutations, can be inherited or newly created. When certain alterations are combined, a cell and its progeny can begin to grow in an abnormal, uncontrolled fashion that is the hallmark of cancer. Other inherited and environmental influences can come into play and while these are not mutations, they are no less critical in determining whether or not a cell and its progeny progress to cancer. Some factors appear to prevent cancer, while others promote it. Thus, a central concept in our understanding of cancer is that it does not arise from a single event, but results from many changes and influences on a cell.

The list of environmental factors that can influence the development of cancer is diverse, particularly when we consider the environment in its broadest sense. Potential cancer-causing agents are present in our diets, tobacco smoke, alcohol, home and workplace environments, outdoor air, water, soil, sunlight, certain infectious agents, and some medical therapies. Physiological factors, including hormones and exercise, can also influence the development of cancer. Our inherited factors are also diverse. They are responsible for individual differences in the structure and function of proteins that activate and deactivate chemical substances, repair DNA, control cell growth, and foster immunity. Inherited variations in these proteins are common in the population.

For a single individual, it is impossible to determine with confidence the multiple factors that promoted his or her cancer. However, population studies have revealed patterns and suggest specific factors that increase risk for groups of people. Based on various studies, it appears that environmental factors such as tobacco, diet, infections, occupational exposures, etc., are involved to some degree in 75% to 90% of cancers, both alone and in combination with inherited factors.^{1,2} In the United States, it has been estimated that tobacco is a contributor in approximately 30% of cancers, dietary factors 35%, infections 10%, occupational exposures 8%, natural sources of ionizing radiation 2%, and chemical pollution 2%.^{3,4,5} While the accuracy of these estimates remain a matter of significant debate, they do indicate a substantial target for prevention.

Since environmental physical and chemical factors are known to play a role in the development of some cancers, it may be possible to prevent some cancers by alter-

ing exposures to these factors. Exposures to harmful agents can be reduced, or even eliminated, by avoiding the creation and release of cancer-causing agents, removing them from one's surroundings, and by changing personal behaviors. It is helpful to know where exposures are greatest, and what behaviors and susceptibilities put people at greatest risk, in order for cancer prevention efforts to be most efficient. Some of the most powerful evidence for widespread environmental carcinogen exposure points to cigarette smoke. The extent to which voluntary and involuntary exposure to cigarette smoke can be controlled is a complex issue, and another chapter has been devoted to this subject. Also, emerging evidence suggests that there are environmental factors that are protective, including some dietary choices, physical activity, and other modifiable behaviors. Positive choices and the environmental conditions that encourage them are part of a comprehensive strategy to reduce environmental cancer risk.

The following discussion and recommendations focus primarily on environmental agents over which we have relatively limited personal control. Cancer prevention strategies for these agents need to be established at the national, state, and/or county level. Cancer prevention opportunities for factors that are more easily addressed on an individual basis, such as tobacco use, diet, physical exercise, and ultraviolet radiation, as well as policy changes are discussed in other chapters of this report.

Identifying the Link Between Cancer and Environmental Exposures

Current Approaches

While animal studies provide strong evidence that chemicals and radiation can cause cancer, identifying these agents as causative factors in human cancers is not a simple task. This is due in part to the many factors that interact to cause cancer, the time that must elapse between exposure to an environmental agent and the development of detectable cancer, lack of information regarding the extent of exposure, the lack of basic information regarding the cancer-causing potential of many agents, and the rare occurrence of some cancers. Many of the links between cancer and environmental exposures to date have been made through occupational studies for which at least some data were available on exposures to specific agents for defined worker populations. Community-based cancer surveillance is currently developing as a tool to identify envi-

ronmental and occupational causes of cancer, however, it is one of the most difficult challenges in public health.

Community-based cancer surveillance studies

Cancer surveillance studies rely on the availability of good data, which can come from several sources. One of the best sources is the database maintained by the Maryland Cancer Registry. Other sources include Vital Records, occupational data collected by companies, unions, and insurance companies, and data from published studies around the world.

One difficulty in community-based cancer surveillance is that some types of cancers are very common, while others are quite rare. Given the large and complex picture of cancer occurrence in communities, accurate data on cancer cases are an irreplaceable asset. Thus, the Maryland Cancer Registry works closely with hospitals, doctors, health care provider systems, and state and local health departments to identify each and every cancer case that occurs in the state. It is a challenge to record the correct diagnosis, document where and when treatment has occurred, verify the vital status of the patients, and check the accuracy of the demographic and residential data reported by the patients. Despite these challenges, the Maryland Cancer Registry has received the gold standard from the National Association of Central Cancer Registries in 2001, 2002, and 2003 for data quality and completeness.

One of the most important types of data collected by the Maryland Cancer Registry which helps link cancers to environmental conditions are data about where people are living when they are diagnosed with cancer. In order to determine if there are unusual groupings of cancers in a geographic region or unexpected increases of cancers over time (both phenomena are suggestive of possible environmental factors) cancer registry data can be converted into cancer rates and mapped. As mapping technologies have become more advanced, especially through the development of special computer software called Geographic Information Systems (GIS), the identification of regions of concern has become easier. A challenge remains, however, in determining why cancer rates are sometimes markedly higher in one particular area or during one particular time period. Although this may likely reflect demographic rather than true environmental risk differences, such differences require explanation. The success in finding the causes of locally elevated cancer rates has been very limited across the country, in part due to the limitations in available investigative tools. Difficulties arise

because some people frequently move and experience a variety of environmental exposures over their lifetimes. The long time period between exposure and the appearance of disease makes linkages to specific exposures difficult. Also, personal factors like smoking and genetics influence individual risk. Recent trends in cancer incidence and mortality in Maryland, however, show that rates of lung cancer, bladder cancer, multiple myeloma, and certain other malignancies are much higher than expected in certain parts of the state. Such trends, which raise concerns regarding environmental and occupational factors, have also been observed in other areas of the country.

When cancer rate calculations and maps document patterns suggestive of environmental influences, a variety of methods and tools can come into play to explore the link between the disease and possible exposures to carcinogens. Investigators may first consult the scientific literature to determine whether there are any reported associations. The International Agency for Research on Cancer (IARC) (<http://monographs.iarc.fr/monoeval/grlist.html>) and the National Toxicology Program (NTP) (<http://ntp-server.niehs.nih.gov/>) are two agencies that have developed lists of known human carcinogens and probable human carcinogens based on their evaluation of the strength of available data for each chemical or physical agent. NTP has recently issued its 10th Report on Carcinogens (<http://ehp.niehs.nih.gov/roc/>) which lists over 45 agents or mixtures as known carcinogens based on their conclusion that there is sufficient evidence from studies in humans to indicate a firm relationship between exposure and human cancer. In addition, over 150 compounds or mixtures are listed as "reasonably anticipated to be human carcinogens." Examples of associations between environmental agents and specific human cancers derived from NTP's 10th Report on Carcinogens are listed in Table 8.1.

If published evidence of an association between the cancer of concern and specific environmental chemical exposures is found, local and state health agencies and community groups in partnership can search for records of the use of these chemicals in the area, including historical practices, or a history of local use of these substances. If records exist, the investigating team may assess the levels of exposure and the risks posed by those exposures. Exposure assessment is a key step, because the presence of a hazard does not necessarily mean that exposures have occurred. One additional approach that can be taken is to link cancer incidence maps with environmental data. The same GIS tools that produce the cancer maps can overlay environ-

mental hazard and exposure data with cancer incidence data to determine whether the patterns converge (suggesting possible links between cancers and exposures to carcinogens in a region) or diverge (suggesting that other factors may be responsible for the cancer occurrences in the region). Although maps may raise the possibility of an environmental association, it is again important to assess the true extent of exposure. However, resources to collect environmental data and conduct these assessments are often limited, and local and state expertise may not be sufficient to deal with the problems. Assistance from public and private universities may be critical in deciding how to investigate suspected environmentally caused cancer outbreaks when and if they merit detailed investigation.

Cancer cluster evaluations

Most requests for cancer cluster investigations from members of the public or even physicians require only cursory study since they are generally not real clusters (i.e. rates are not above expected) but are the product of enhanced local surveillance due to interactions that occur between cancer victims and their families or friends. There is often a sincere belief that something must be causing a perceived cluster, which leads to a demand for environmental testing. Yet most investigations under these circumstances yield little information. The Centers for Disease Control and Prevention (CDC), recognizing that environmental studies of this type seldom yield useful results, has issued guidance to the states that limit excursions in this line of research. The CDC recommends that reported cancer clusters should be approached with caution and the numbers checked before attempts are made to find causes for the occurrences. Even confirmed differences in cancer rates in a given geographic area or time period may still be due to chance. Local health departments do not always have the resources to provide good answers to communities that believe they have unusually high rates of cancer. Data must be made available and analyzed rapidly so that community members understand the true picture early in any investigation. As a general rule, the public more readily accepts the conclusions of experts they view as independent. In particular, the input from experts in academic centers can alleviate concerns and prevent needless expenditures for environmental testing, or conversely, ensure that studies are done when they are appropriate and may lead to helpful findings.

Availability of Databases

As noted earlier, Maryland is fortunate to have a high-quality cancer registry capable of locating and charac-

Table 8.1
Examples of Associations Between Environmental Agents and Cancer

Cancer Site	Agent/Substance/Mixture
Bladder	Tobacco smoke; benzidine and dyes metabolized to benzidine; arsenic; coal tar pitches
Leukemia	Benzene; butadiene; ethylene oxide
Liver and intrahepatic bile duct	Alcoholic beverage consumption; vinyl chloride; thorium dioxide; aflatoxins; arsenic
Lung and bronchus	Tobacco smoke; mustard gas; asbestos, radon; wood dust; coal tar pitches
Lymphoma (non-Hodgkins)	Ultraviolet radiation, broad spectrum; 2,3,7,8-TCDD; 1,3-butadiene
Multiple myeloma	Benzene; vinyl chloride; 2,3,7,8-TCDD

Source: Report on Carcinogens, 10th Edition; U.S. Department of Health and Human Services, Public Health Service, National Toxicology Program, December 2002.

terizing cancer incidence in the state. Access to the Maryland Cancer Registry data is open to qualified investigators and safeguards are in place to protect the privacy of the patients in the database. The registry has been expanding its capability to conduct fine-scale geographic studies, and residential data are now being routinely coded in such a way as to give investigators access to fine-scale geographic information, providing considerable savings in time and effort. This is, then, one of the best starting places for cancer surveillance data.

Data about the occurrence of environmental carcinogens are much less centralized than cancer incidence information and the utility of the data is variable. Datasets about environmental conditions are produced for various purposes by local, state, and national agencies and other institutions. A preliminary look at these datasets reveals that some are detailed and easily obtainable while others have notable gaps and are difficult to obtain. It is not uncommon to find that data collected for one purpose, such as monitoring permits or grading the progress of government programs, lack the type of information necessary to assess cancer risk. In these cases, the data could be used to generate hypotheses that may in turn guide future data collection efforts.

Some of the limitations that exist in currently available databases are summarized below to illustrate the types of efforts that need to be supported to enhance our ability to address environmental and occupational factors in Maryland's cancer incidence. This list is not intended to be comprehensive.

Occupational exposure datasets

Statewide data regarding cancer in occupational groups in the state are limited. The Maryland Cancer Registry collects data about the current occupation of a person diagnosed with cancer, but in some instances the data are not informative (for example, persons may report their occupation as "none" or "retired"), and in other instances the occupation of a deceased person may have been reported inaccurately by the next-of-kin. Documenting occupational histories usually proves difficult and data from the past are needed, given the latency between exposure and the onset of cancer.

Exposure data for chemical carcinogens in the workplace are also difficult to obtain. Employers are required to have lists of all hazardous substances used on the premises and workers usually receive training in how to safely handle these substances. Although the Maryland Department of the Environment (MDE) maintains a

centrally organized repository for these lists that can be used to track changes in these materials over time for a particular facility, this information does not lend itself to calculations of worker exposure levels.

Non-occupational exposures

There are numerous sources of data that address environmental conditions in the state with particular reference to chemical and radiation exposures. The following examples of public data sources are listed because they contain geographic information in grid (exact location) format, which is an ideal data representation for modeling and statistical analysis over regions, allowing investigators to put together the potential hazard maps with population density and with changes in the regions over time. This is not a comprehensive list, but it provides examples of the types of databases that are helpful for investigations of environmental factors in cancer development and includes a discussion of their limitations.

- Land use data are available from the Maryland Department of Planning from 1990 onward. These data consist of aerial surveys (also called remote sensing), which depict the type of cover and activities that exist across the landscape, from housing to orchards, forests, crops, and industrial facilities. This dataset is limited by a lack of data prior to 1990 and needs to be continually updated to reflect changes in land use over time.
- The Environmental Protection Agency's (EPA) Toxics Release Inventory provides data about regulated releases of toxic chemicals into the air, surface water, and soil from 1987 onward. These data are reported by companies as the total pounds of each chemical released per year. While valuable, this data set is limited by the fact that reporting is limited to facilities that meet certain criteria (e.g., the release of certain types of chemical compounds and chemical classes, the type of industry, the number of employees, and the quantity of compounds used). Also, the amounts of released material reported may be estimated rather than measured, and certain chemicals are lumped into larger chemical classes. Exposure modeling is difficult since the amounts released are only reported as yearly totals.
- Some data sources providing information about the quality of drinking water, surface water, and ground water in Maryland are as follows:
 - The United States Geological Society (USGS) and the Maryland Geological Society (MGS) datasets identify and characterize surface waters and aquifers (underground sources of water) in Maryland and show their locations in specific regions. Most, but not all, well water in the state comes from these deep aquifers. Chemical data for a limited number of chemicals such as pesticides are also available. Although helpful, there are challenges to the use of these data because they are organized by drainage basin and other criteria, not by routinely used census or other political boundaries. Also, since chemical concentrations in groundwater can vary due to seasonal use of the chemicals and changes in groundwater flow due to rainfall in the region, the limited chemical sampling may misrepresent actual human exposures.
 - Historical records of public drinking water data exist for nitrates, volatile organic compounds, pesticides, and certain heavy metals. Two systems, the Washington Suburban Sanitary Commission and Baltimore City, supply 80% of Maryland residences with drinking water from municipal water systems and these facilities maintain extensive water quality databases. Additional data from groundwater contamination sites near public water system raw water sources can be obtained from MDE source water assessment plans that are currently being prepared. These plans are scheduled for completion in FY 2003. These data address only the organic and inorganic chemicals mandated by the EPA for routine testing of public water systems.
 - For private wells, it is difficult to obtain water quality data because current regulations only require testing at the time of well construction and the data are not compiled. The geographic information is often limited. Private wells serve the homes of approximately 16% of Maryland residents.
 - The Maryland Department of the Environment maintains discharge monitoring data from permitted industrial and municipal facilities around the state. Data regarding specific toxic and conventional pollutants discharged to surface waters can be retrieved on a facility and watershed basis.
 - Maryland's Department of the Environment operates monitors for certain air pollutants. Air monitoring stations are limited in number and generally designed for statewide or regional esti-

mates and compliance with EPA air pollution control targets. Additional monitoring stations are needed to generate air quality data for airborne carcinogens for areas of the state not currently covered by existing stations.

- Maryland's Department of the Environment and the EPA regulate the generation and disposal of hazardous materials. Hazardous waste sites are evaluated for their potential to release toxic chemicals into the surrounding soil, air, underground water, and surface waterways. Information about possible routes of human exposure, compounds present at the site, and dates of operation are available from the EPA CERCLIS database and the Department of the Environment. Specific chemical sampling data for individual sites are difficult to access, however, and nearby land use often changes over time.

Infectious Agents

With knowledge of the nature of carcinogenesis and the importance of cell injury and repair comes a growing understanding of why some infectious agents play an important role in cancer causation. With ongoing cell damage caused by chronic viral infections and repeated repair, the opportunity for DNA "mistakes" grows. The immune status of an individual may also be altered by exposure to biological agents. Research and education on the role of biological agents in cancer causation could lead to better cancer controls through the development of interventions such as vaccines and antibiotics and changes in personal behavior.

Several infectious agents have already been linked to cancer. The Epstein-Barr virus has been implicated in some forms of lymphatic cancer. The human papillomavirus (HPV) has been linked to cervical cancer and more recently to cancer of the head and neck. HPV has also been postulated as a risk factor for prostate cancer. Hepatitis B and C have been linked to primary liver cancer. Stomach cancer is strongly associated with another infectious agent, *Helicobacter pylori*, which is also associated with gastrointestinal problems. HIV, the virus that causes AIDS, has also been linked to Kaposi's sarcoma and cervical cancer.

For each of these agents, strategies to address them should be linked to, and recognized as, part of cancer control efforts. When no strategy has been identified, research should continue with at least equal enthusiasm as has been applied to chemical agents. Possible

public health strategies include vaccine delivery to high-risk groups, screening, infection control efforts and, when appropriate, treatment. Databases exist for viral hepatitis as a reportable disease but other cancer-causing infections are not routinely tracked.

Cancer Disparities

The cancer disparities chapter (chapter three of this report) describes several examples of persisting differences in cancer rates between different socioeconomic and ethnic groups and sexes. These differences can be difficult to explain, but it is important to consider the potential role of factors that influence exposure to environmental carcinogens. Proximity to pollution sources, occupations, awareness and attitudes regarding risks, cultural norms, and individual practices regarding diet and other personal behaviors are examples of factors that have the potential to affect environmental exposures. Social injustices prevent some individuals from achieving quality education, housing, and employment, as well as adequate access to health insurance and health care. Circumstances such as these make it difficult for communities and individuals alike to develop preventive health behaviors, utilize cancer screening, and respond to health issues. At the other end of the spectrum, genetic susceptibility to cancer is an emerging area of research that may eventually help identify different levels of risk for individuals and groups within a population.

Environmental Cancer Prevention Programs

Many agencies and institutions within the state conduct activities that promote cancer prevention. These include research, education, and regulatory activities aimed at limiting exposures to known carcinogens. Many existing programs are designed to address lifestyle issues such as diet and exercise. Others promote cancer screening, the reduced use of tobacco products, the proper handling of hazardous materials such as pesticides, safe fish consumption, and stricter regulation of industrial discharges to waterways and air. Although most of these programs are generally considered to be effective, there has been little follow-up to accurately determine their impact. Assessing the effectiveness of these programs designed to prevent direct exposures to carcinogens would make it possible to judge whether they should be continued and/or how they can be improved.

In the early 1990s, in response to public concern, increased attention was given to identifying the exposure of specific populations to known environmental carcinogens, such as radon gas. In addition to sampling to document exposures and risk assessments to characterize the risk, public education programs were developed to inform people of appropriate actions that they could take to limit their exposures to contaminants. Town meetings, fact sheets, and news media were useful tools for communicating with the public. However, identifying and communicating directly with specific “stakeholders” in the community about the development of solutions to specific problems was a key factor in the success of these programs. This approach is an integral part of cancer prevention efforts.

Conclusion

The following goals and objectives are by no means an exhaustive list, but represent areas in which the Environmental Issues and Cancer Committee felt significant progress could be made in cancer control efforts at this time. Recent advancements in our knowledge of the role of environmental factors in cancer causation and promotion provide a foundation for moving ahead in the development of databases and tools needed to better identify linkages between cancer incidence and chronic infections and/or exposures to chemical and physical carcinogens in Maryland. As our understanding of the relative importance of specific environmental factors in cancer incidence grows, we can more effectively develop strategies to reduce exposures to the most important factors through source control and avoidance behaviors. Cancer control goals can best be achieved through the development of collaborative teams that include citizens, researchers from academic institutions, and public health professionals from our county and state governments.

Healthy People 2010 Objectives

The following are Healthy People 2010 objectives⁶ related to environmental health:

Objective:

Reduce exposure of the population to pesticides, heavy metals, and other toxic chemicals, as measured by blood and urine concentrations of the substances or their metabolites.

The U.S. baseline: Developmental

Objective:

Improve the quality, utility, awareness, and use of existing information systems for environmental health.

The U.S. baseline: Developmental



Environmental Issues and Cancer Goals, Objectives, and Strategies

Goal:

Improve prevention of environmentally related cancers through:

- better evaluation of existing cancer prevention programs.
- increased knowledge of environmental and occupational carcinogen exposures among scientists, health agencies, and the public.
- increased efforts to reduce exposures to environmental carcinogens.
- increased surveillance of occupational cancers.
- improved links between academic research institutions and state and local health departments.
- increased efforts to control infections known to increase cancer risk.
- increased efforts, including community involvement, toward programs designed to identify and address factors contributing to cancer disparities.

Targets for Change

By 2008, improve the quality, utility, and use of databases for environmental carcinogens that will enhance exposure assessment.

By 2008, improve the capacity to measure bioindicators, measure the levels of compounds in the environment, and use other means to estimate environmental exposures at the population level.

By 2008, strengthen the practice of dual appointments or establish other formal cooperative relationships between academic institutions and state and local public health agencies.

By 2008, improve the capacity to identify and prevent occupationally related cancer.

Objective 1:

Improve cancer prevention program evaluation.

Strategies:

1. Create a primary prevention committee within the State Council on Cancer Control to ensure that environmental as well as lifestyle issues receive appropriate attention.
2. Support efforts to measure the effectiveness of primary prevention programs and policies, including their impact on toxic exposures and cancer.

Objective 2:

Improve data collection and carcinogen exposure assessment.

Strategies:

1. Explore ways to improve regulatory data collection efforts for cancer hazard assessment and tracking.
2. Support the development of an environmental health tracking system in Maryland.
3. Improve the accessibility and utility of environmental-monitoring data by computerizing databases and geo-coding data.
4. Enhance the capacity of state public health and other laboratories to test for the presence of environmental agents and related biomarkers in urine, blood, and other tissue samples.
5. Explore approaches for the expanded monitoring of commercial and noncommercial pesticide use.
6. Expand the capacity of the state to monitor ambient air toxics.
7. Support the development of a strategy for comprehensive, private well water testing and monitoring.

**Objective 3:**

Improve information regarding occupational risk factors for cancer.

Strategies:

1. Explore opportunities for matching employee databases (from specific industries, trade organizations, etc.) with the state's cancer database in order to better characterize the role of occupation in cancer.
2. Establish an interdisciplinary task force to develop recommendations for occupational cancer investigations in Maryland.

Objective 4:

Enhance collaboration between academic research institutions and state and local public health departments.

Strategies:

1. Develop a formal and adequately funded linkage between academic and government resources to bring their respective teaching, research, and practice agendas in sync with one another. Explore models to make this happen in both the short and long term.
2. Develop a contingency plan for responding to citizen concerns regarding possible cancer clusters that cannot be appropriately handled via routine risk communication and statistical analysis; this plan should include specific contact individuals at local universities.
3. Promote the training of physicians and environmental scientists in occupational and environmental cancer research at Maryland's universities and institutions.
4. Promote the sharing of expertise between the research and practice communities through joint programs such as a "Grand Rounds in Environmental Health" series.

**Objective 5:**

Improve recognition and screening for cancers associated with infectious agents.

Strategies:

1. Encourage screening for human papilloma viruses (HPV) and support efforts to develop a vaccine for HPV.
2. Promote immunization for the Hepatitis B virus.
3. Support stronger efforts to control blood-borne infections.
4. Consider a recommendation that encourages physicians to test for and treat *Helicobacter pylori* infection in accordance with the American College of Gastroenterology practice guidelines.
5. Promote implementation of guidelines from the National Institutes of Health (NIH) and CDC for the control of Hepatitis C.

Objective 6:

Reduce the differences in cancer rates attributable to socioeconomic status or racial status.

Strategies:

1. Develop a comprehensive public participation plan as a component of the state's cancer control initiative.
2. Create community environmental health characterizations or profiles that may be used to support decision making, priority setting, and the focusing of limited resources in order to best limit exposures and increase accessibility to better preventive health care.
3. Undertake comparative research to better understand and explain different cancer rates between groups.
4. Support community health centers and technical assistance in local communities in order to increase cancer screening and awareness of environmental health issues.
5. Make health care services more culturally acceptable and appropriate.
6. Enhance community planning and zoning processes to reduce health risks by reducing exposures.
7. Continue efforts to document differences in cancer rates among different regions and populations.

Resources

Readers who want more detailed information on the issues presented in this chapter are directed to the websites listed below.

National Toxicology Program Report on Carcinogens

<http://ehp.niehs.nih.gov/roc>

International Agency for Research on Cancer

<http://monographs.iarc.fr/monoeval/grlist.html>

American Cancer Society

Environmental & Occupational Cancer Risks
[http://www.cancer.org/docroot/PED/ped_1_1.asp?
siteArea=WHO](http://www.cancer.org/docroot/PED/ped_1_1.asp?siteArea=WHO)

Centers for Disease Control and Prevention

Investigating Clusters of Health Events
http://www.cdc.gov/nccdphp/drh/sata_hlevent.htm

Centers for Disease Control and Prevention

Cancer Cluster Frequently Asked Questions
<http://www.cdc.gov/nceh/clusters/faq.htm>

Maryland Department of Health & Mental Hygiene

A Message About Cancer Clusters
http://www.cha.state.md.us/oeh/pdf/cancer_clusters.pdf

National Institute of Occupational Safety and Health

Occupational Cancers
<http://www.cdc.gov/niosh/occancer.html>

National Academy of Sciences

Carcinogens and Anticarcinogens in the Human Diet
<http://www.nap.edu/readingroom/books/diet/index.html>

U.S. Environmental Protection Agency

National-Scale Air Toxics Assessment for 1996
<http://www.epa.gov/ttn/atw/sab/sabrev.html>

Current Drinking Water Standards and MCLs
<http://www.epa.gov/safewater/mcl.html>

Agency for Toxic Substances and Disease Registry (ATSDR)

Homepage and link to ToxFAQs
<http://www.atsdr.cdc.gov/>

National Library of Medicine

Hazardous substances data bank and other resources in TOXNET
<http://toxnet.nlm.nih.gov/>

Environmental/chemical databases:

Agricultural pesticide use
<http://water.usgs.gov/pubs/>

Hydrography data
<http://nhd.usgs.gov>

Brownfields areas in Maryland
[http://www.mde.state.md.us/programs/landprograms/
errp_brownfields/index.asp](http://www.mde.state.md.us/programs/landprograms/errp_brownfields/index.asp)

Air pollution data
<http://www.epa.gov/air/data/index.html>

Air pollution maps
[http://www.epa.gov/air/data/repsst.html?st~MD
~Maryland](http://www.epa.gov/air/data/repsst.html?st~MD~Maryland)

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- 1 Davis DL, Muir C. Estimating avoidable causes of cancer. Environ Health Perspect 1995 Nov;103(Suppl)8:301–6.
- 2 Hoover RN. Cancer—nature, nurture, or both. N Engl J Med 2000 Jul 13;343(2):135–6.
- 3 See note 1.
- 4 Doll R, Peto R. The causes of cancer: quantitative estimates of avoidable risks of cancer in the United States today. J Natl Cancer Inst 1981 Jun;66(6):1191–1308.
- 5 U.S. Environmental Protection Agency. Unfinished business: a comparative assessment of environmental problems. Appendix I to report of the cancer risk work group. February 1987.
- 6 U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy People 2010, Volumes I and II (2nd ed.). Washington, D.C.: November 2000. (Accessed at <http://www.healthypeople.gov/Document/tableofcontents.htm>.)

CHAPTER 9

COLORECTAL CANCER

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COLORECTAL CANCER

Cancer of the colon and rectum (CRC) is the second leading cause of cancer deaths and the fourth leading cause of new cancer cases in Maryland. Maryland's death rate from colorectal cancer is sixth in the United States. It is believed that CRC is caused by a complex interaction of inherited susceptibility and environmental factors.¹ Within the large intestine, genetic changes alter the growth of normal cells to form adenomatous polyps (adenomas). Adenomas are common; they are found in approximately 25% of people by age 50 and the prevalence increases with age.² Seventy to ninety percent of CRC is believed to arise from these adenomatous polyps.³ Overall, about 10.5% of adenomas will progress to CRC; however, 50% of large adenomas (over two centimeters) will progress

to cancer. Adenomatous polyps with villous features are more likely to progress to cancer than those with only tubular pathology (e.g., 20% of villous adenomas and 4% of tubular adenomas will progress). The average time between the development of a polyp and its progression to CRC is 10–15 years.⁴

Ninety-eight percent of CRC is adenocarcinoma.⁵ Other malignant tumors of the colon and rectum include carcinoid tumors and lymphomas. The extent of the tumor at the time of diagnosis is the most important factor in predicting survival. SEER stages⁶ for CRC used by the Maryland Cancer Registry (MCR) include “local” for tumors that invade to the submucosa or through the muscle (T1-3); “regional” for tumors that are either locally invasive and have spread to adjacent organs or structures or those that have spread to regional lymph nodes; and “distant” for tumors that have spread to distant lymph nodes or other organs, especially the liver, lungs, and bones.⁷ “In situ” tumors, in which the cancer is localized to the polyp, are reportable but are not included in the MCR or national CRC statistics. Survival rates five years after diagnosis are 90.1% for local, 65.2% for regional, and 8.8% for distant staged tumors.⁸ Survival rates for whites exceed those for blacks for all stages, and the survival rate of cancer of the colon exceeds that of cancer of the rectum.

Because adenomatous polyps are precursors to CRC, removal of these polyps reduces the subsequent incidence and mortality of CRC.⁹ The incidence rate of CRC could be reduced by an estimated 70%–90% by the screening and removal of polyps.¹⁰

Risk Factors

Certain risk factors may increase the chance of developing CRC, including the following:

Age

Age is the biggest risk factor for CRC. Of the 2,547 cases of CRC diagnosed in Maryland in 1999, 92.0% were diagnosed in people aged 50 or older.

Family History

Family history of CRC or adenomas increases a person's risk of colorectal cancer.¹¹ People with familial adenomatous polyposis (FAP) have a mutation in the APC tumor-suppressor gene and their risk of CRC is almost 100%.¹² Those with hereditary non-polyposis colon cancer (HNPCC) have mutations of human mismatch repair genes and have an 80% or higher risk of CRC by age 70 as well as increased risk of cancers of the endometrium, stomach, ovary, brain, kidney, and biliary tract and gallbladder.

People with two or more first degree relatives of any age or one first-degree relative diagnosed with CRC at less than 50 years of age have three to four times the risk of colorectal cancer than people without first degree relatives with colorectal cancer. Those with one first degree relative with CRC at 60 years or older have almost twice the risk of those without a close family history of CRC.¹³ It is estimated that 1% of all CRC occurs in people with FAP, 5% with HNPCC, 15–20% with other family history; and approximately 75% are “sporadic” cases occurring in people with no family or personal history of CRC or adenomas and no personal history of inflammatory bowel disease.¹⁴

Personal History

People with a history of CRC, adenomatous polyps, inflammatory bowel disease (ulcerative colitis or Crohn's colitis), or women with prior ovarian or endometrial cancer are at increased risk of CRC. The risk of CRC in people with a history of inflammatory bowel disease is approximately 30% after 10 years. Prior breast cancer appears to confer little^{15,16} or no¹⁷ increase in the risk of CRC.

Other Lifestyle Risks

Other risk factors that increase the risk of CRC include: diets high in fat, protein, calories, alcohol, and meat; diets low in calcium and folate; physical inactivity; obesity; and smoking.^{18,19} Factors that have been associated with a lower risk of CRC include postmenopausal hormones and aspirin use.

Burden of Colorectal Cancer in Maryland

CRC is the fourth leading cause of new cancer cases reported in Maryland (following lung, breast, and prostate cancers, and excluding non-melanoma skin cancer) and the second leading cause of cancer deaths following lung cancer.²⁰ In 1999, 2,547 people in Maryland were diagnosed with CRC (53.3 cases per 100,000 population, an age-adjusted rate), and 1,059 people died of CRC (22.5 cases per 100,000 population; significantly higher than the U.S. rate of 21.1 cases per 100,000). See Table 9.1 for details.

Maryland ranked sixth in CRC mortality among U.S. states for the time period 1995–1999. Figure 9.1 shows the trend in these cases and deaths from 1995–1999 compared to the U.S. SEER rates. During this period, Maryland had an annual 3.4% decrease in incidence and 3.7% decrease in mortality.²¹

CRC incidence and mortality rates increase markedly with age (Figure 9.2) essentially doubling every decade after the age of 50 years. From 1995–1999, incidence rates declined among men and women of both races in Maryland (Figure 9.3). Incidence rates are higher among men than women and blacks have higher rates than whites for both genders. Mortality rates were highest among black men and were more than twice the rate among white women (37.1 per 100,000 in 1999 vs. 17.8 per 100,000 respectively), with white men and black women having intermediate rates (Figure 9.4). Figure 9.5 shows the colorectal cancer mortality rates from 1995–1999 in Maryland's 24 jurisdictions. Montgomery County had a rate statistically lower than the U.S. rate while eight counties had rates that were statistically higher than the U.S. rate.

In 1999, 30.4% of CRC cases were reported as local stage at the time of diagnosis, 37.8% were regional stage, 17.8% were distant stage, and 14.1% were unstaged. Between 1992 and 1997, 74% of whites had their CRC diagnosed in the local or regional stage com-

Table 9.1
Colorectal Cancer Incidence and Mortality by Race and Sex
in Maryland and the United States, 1999

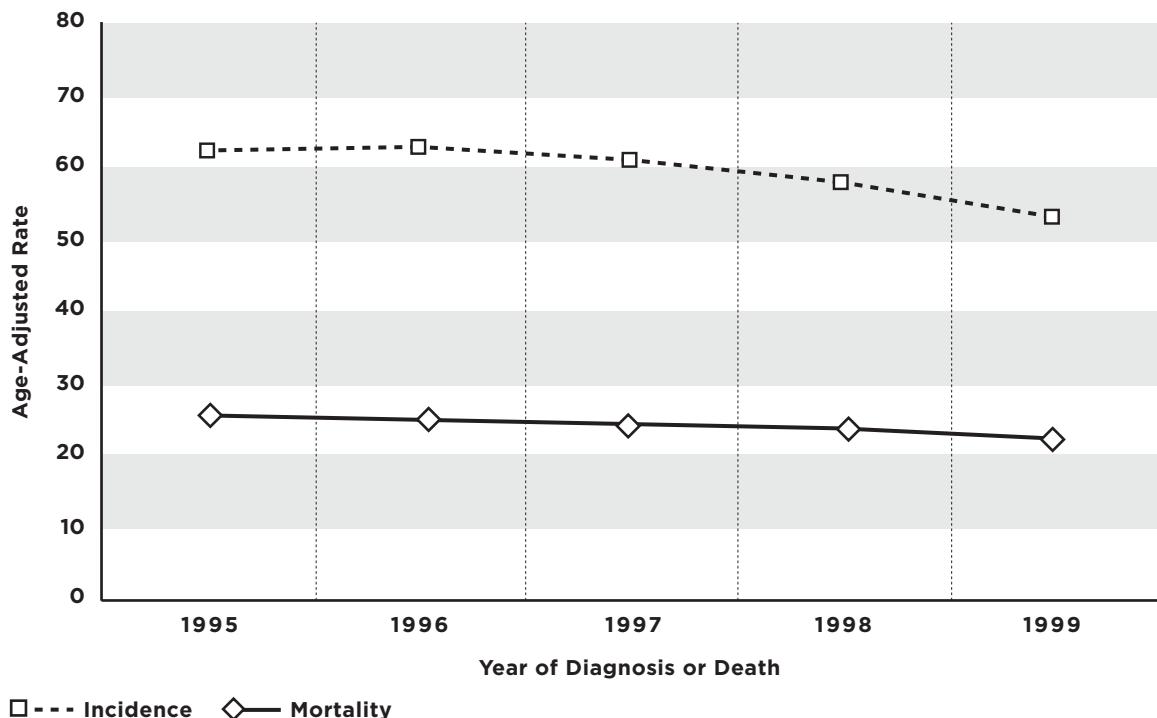
Incidence 1999	Total	Males	Females	Whites	Blacks	Other
New Cases (#)	2,547	1,291	1,256	1,882	540	76
Incidence Rate	53.3	63.4	45.4	50.8	56.4	52.9
U.S. SEER Rate	54.3	63.7	47.1	53.8	61.7	NA
Mortality 1999	Total	Males	Females	Whites	Blacks	Other
MD Deaths (#)	1,059	509	550	763	278	18
MD Mortality Rate	22.5	26.4	19.6	20.6	31.2	**
U.S. Mortality Rate	21.1	25.4	18.0	20.6	28.8	NA

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

**Rates based on cells with 25 or fewer non-zero cases are not presented per DHMH/MCR Data Use Policy.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

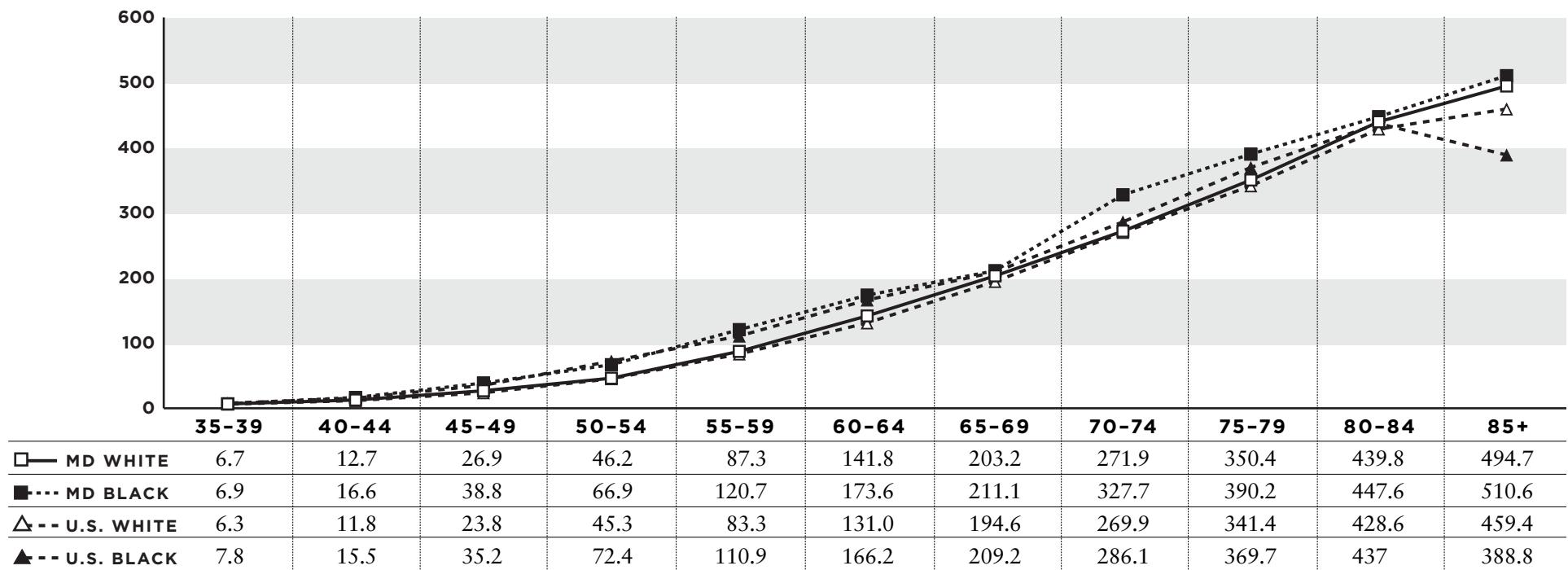
Figure 9.1
Colorectal Cancer Incidence and Mortality by Year of Diagnosis or Death
in Maryland, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; Maryland Division of Health Statistics, 1995-1999.

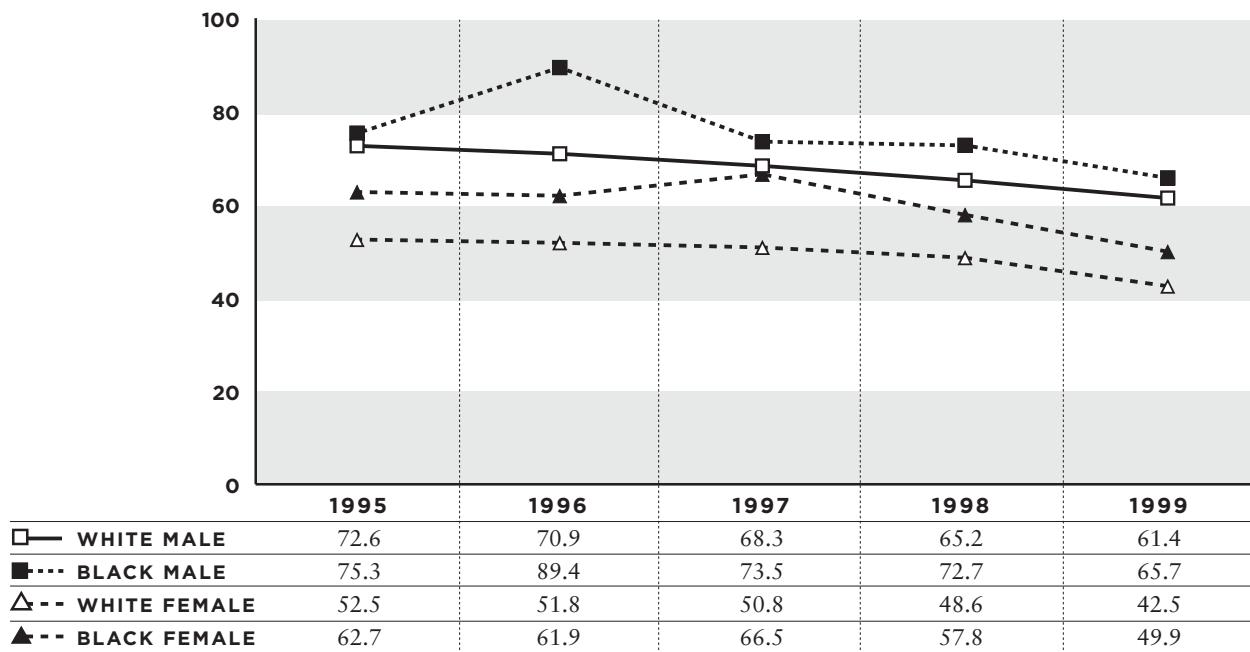
Figure 9.2

Colorectal Cancer Age-Specific Incidence Rates by Race in Maryland and the United States, 1995-1999

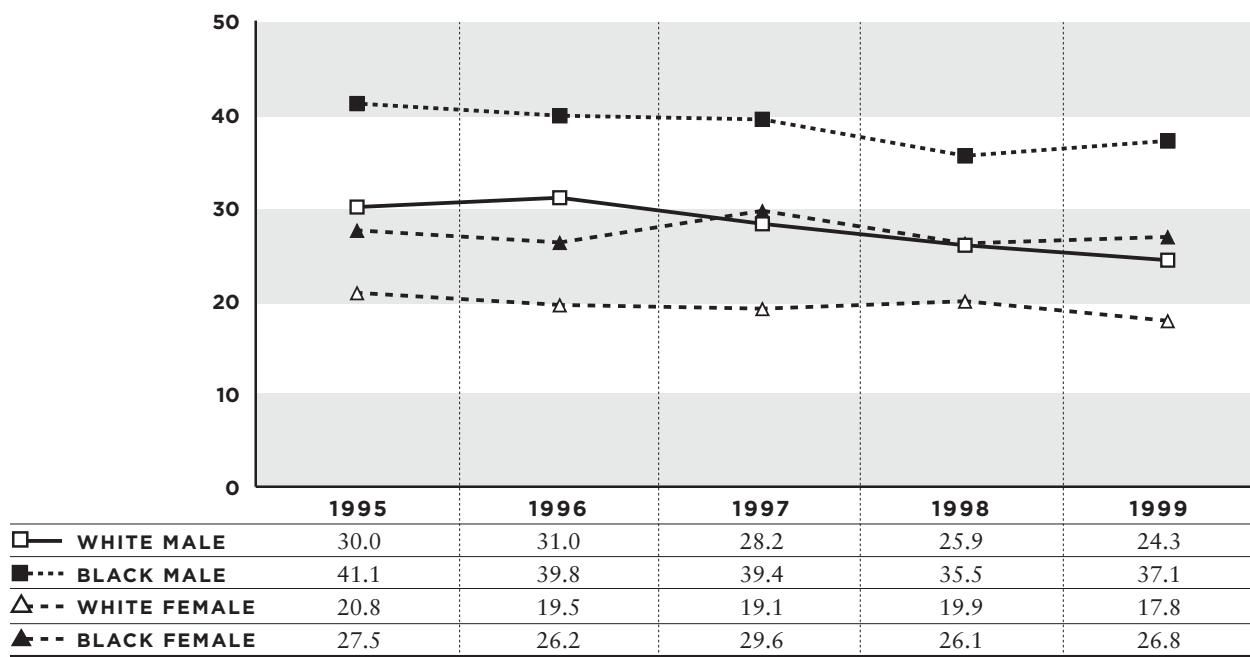


Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

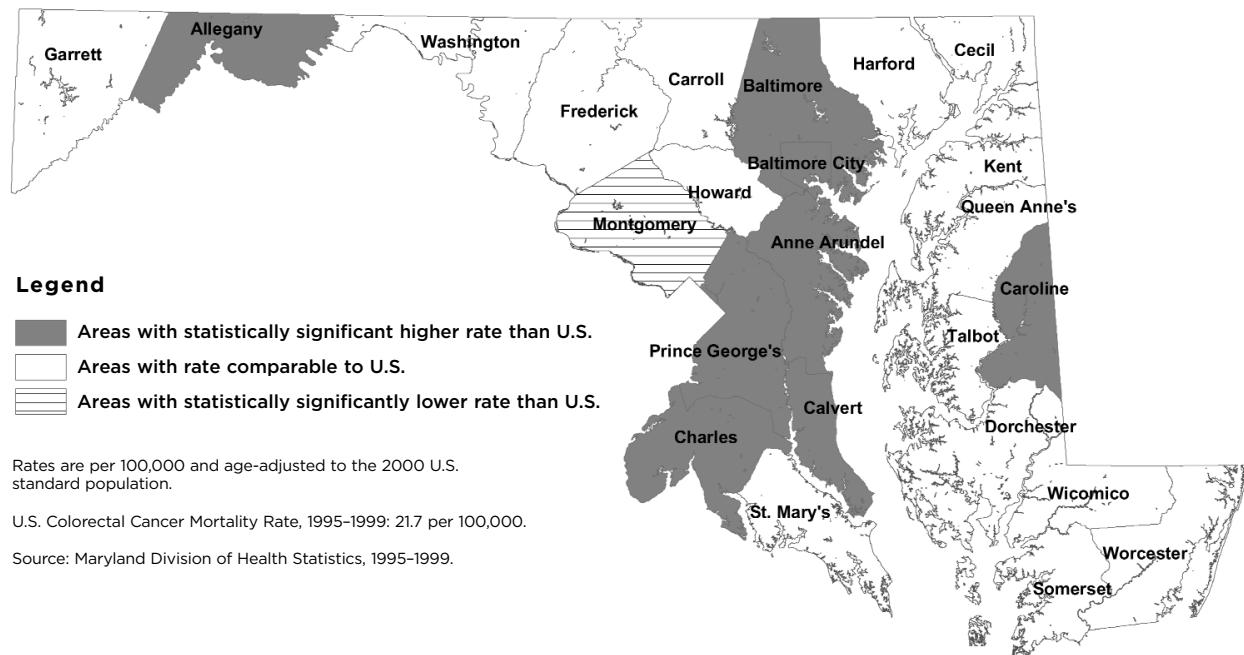
Figure 9.3**Colorectal Cancer Incidence Rates by Race and Sex in Maryland, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999.

Figure 9.4**Colorectal Cancer Mortality Rates by Race and Sex in Maryland, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995-1999.

Figure 9.5
Maryland Colorectal Mortality Rates by Geographical Area:
A Comparison to Rates in the United States, 1995-1999



pared to 69% of blacks. In contrast, 20% of blacks had distant staged CRC at the time of diagnosis compared to 16.4% of whites. Between 1992 and 1999, cases diagnosed at the local stage accounted for about 35% of all cases that were staged. Local, regional, and distant stage distribution (as a percent of the total cases on whom stage has been reported between 1992 and 1999) is shown in Figure 9.6.

Disparities

- Black men have the highest death rates from CRC, followed by white men and black women; white women have the lowest rates—approximately half the rate of black men.
- Twenty percent of blacks have CRC that is in the “distant” stage at the time of diagnosis compared to 16.4% of whites.

Primary Prevention

Primary prevention of colorectal cancer requires adopting behaviors that are believed to lower the risk of colorectal cancer. Certain risk factors for CRC are not modifiable (age, family history, and personal history) while other factors can be modified (weight, diet, and

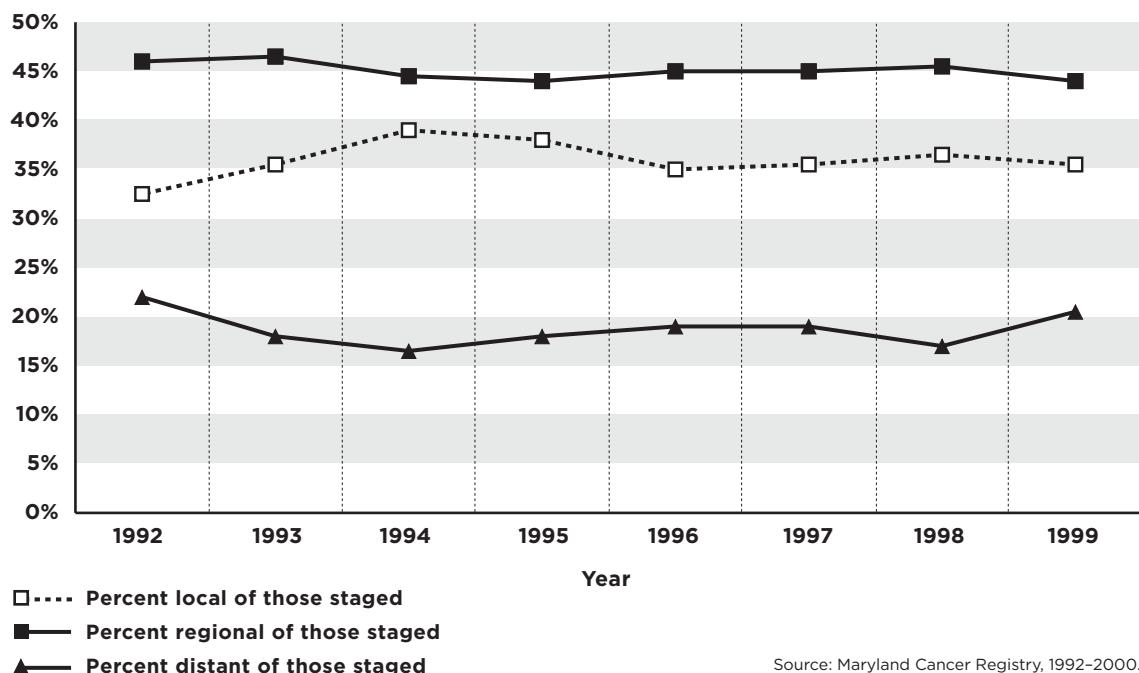
physical inactivity). Additionally, removal of adenomas during colonoscopy is an important primary prevention effort for colorectal cancer.

The current prevalence of CRC lifestyle risk factors in Maryland, including overweight and obesity, inadequate intake of fruits and vegetables, and physical inactivity, are shown in Figure 6.3 in chapter six on diet and physical activity. It is unclear whether adopting lifestyle behaviors that are associated with lower rates of CRC later in adulthood is sufficient to decrease an individual’s risk of CRC.

For this reason, primary prevention recommendations for CRC parallel those recommended for prevention of other cancers, cardiovascular disease, diabetes, and other chronic diseases. These include not smoking, being physically active, eating vegetables and fruits, limiting intake of fats, red meat, and alcohol, achieving and maintaining a healthy weight, and consuming enough folate in one’s diet or via a supplement.²² Medications that may lower the risk of CRC, including non-steroidal anti-inflammatory drugs, are under investigation.

Removal of adenomas during colonoscopy is primary prevention because “polypectomy” takes away the precursor lesion of CRC. Therefore, colonoscopy with polypectomy is not just a screening test for cancer or an

Figure 9.6
Maryland Colorectal Cancer Cases by Stage, 1992-2000



Source: Maryland Cancer Registry, 1992-2000.

attempt to obtain early diagnosis. It is in a special category as it is primary prevention as well. Colonoscopy is further discussed under screening, below.

Screening

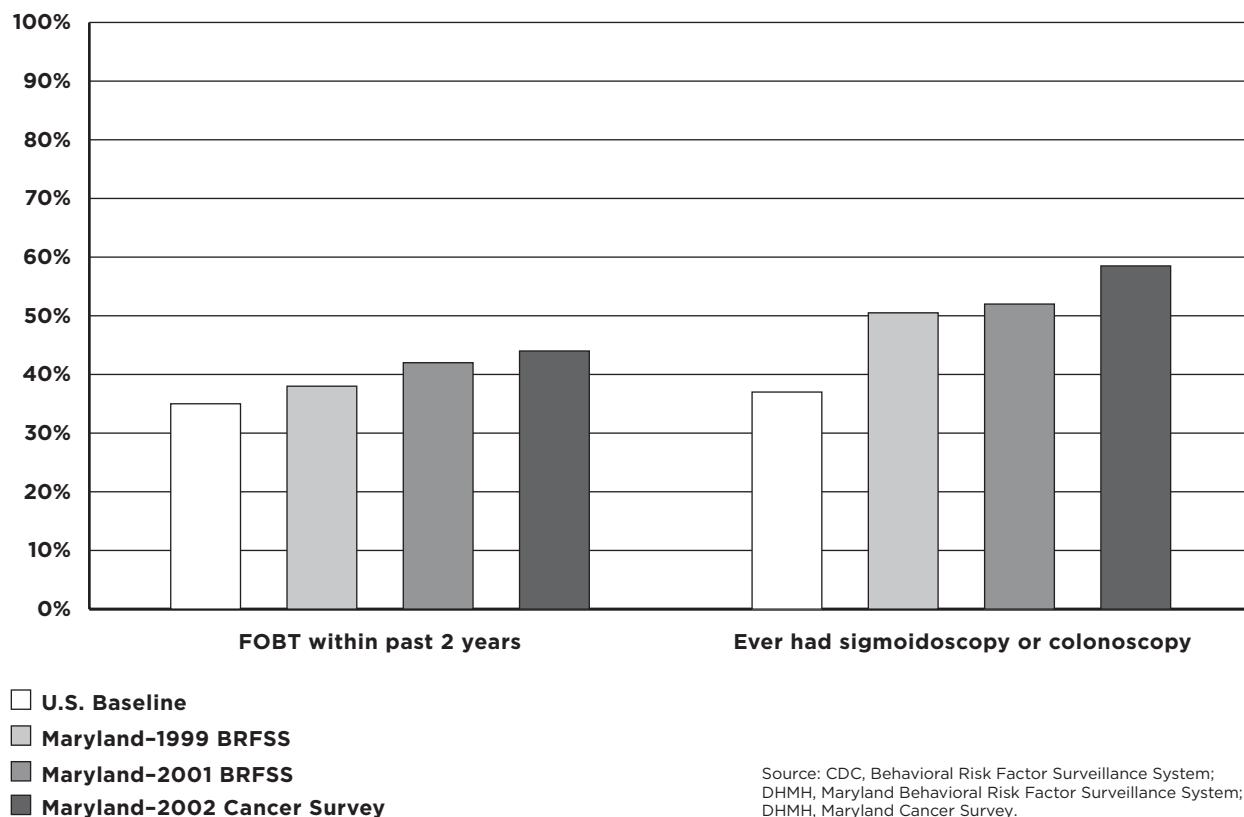
At this time, screening to detect CRC at an early stage consists of either visualizing the inside of the colon or testing for blood in the stool. The colon can be viewed directly either with a colonoscope (a fiber-optic, lighted instrument that views the entire colon from the rectum to the cecum, that is, from the end to the beginning of the large intestine) or a flexible sigmoidoscope (a similar, shorter instrument that views the rectum and descending colon, or, the last third of the colon), or visualized with a double contrast barium enema X-ray exam. During a colonoscopy, any polyp or other suspicious area can be biopsied or removed entirely and sent to the laboratory for diagnosis. Another type of routine testing is the fecal occult blood test (FOBT)—a home test kit that identifies hidden blood in feces samples taken over three days.

The U.S. Preventive Services Task Force,²³ the American Cancer Society,²⁴ the American College of Gastroenterology,²⁵ and the American Gastroenterologic Association²⁶ all recommend screening for CRC begin-

ning at age 50 for those at average risk and earlier for those at increased risk. The Maryland DHMH Medical Advisory Committee concurs and recommends either colonoscopy or FOBT with sigmoidoscopy as the two most effective means of screening people at average risk.²⁷ The Medical Advisory Committee recommends screening with colonoscopy for those at increased risk. The cost-effectiveness of both methods are similar.²⁸ All of the above-mentioned groups agree that any form of CRC screening is preferable to *no* screening. Colonoscopy achieves both early detection of cancers and also primary prevention: by removing adenomatous polyps (“polypectomy”), the precursor lesion is no longer present in the colon to progress into CRC.

Factors that influence patients and providers when choosing a screening test include the risks associated with the testing procedure and the test's accuracy, convenience, and cost.^{29,30} These factors differ for each recommended screening procedure. For example, FOBT has been shown to reduce incidence³¹ and mortality, is inexpensive, and can be done at home, but it must be done annually and has both false positive and false negative results. Colonoscopy is considered the gold standard because it visualizes the entire colon, and polyps can be removed (or tissue biopsied) during the procedure. However, it requires more preparation, time off from work for the patient, is more expensive, and car-

Figure 9.7
Percent of Persons Aged 50 and Older Who Have Had CRC Screening in the U.S. and Maryland



ries a risk of bleeding and colon perforation, especially when polyps are removed or biopsies are taken.

New screening tests are being evaluated but are not currently recommended for routine use. These include computerized tomography (CT) of the colon, or “virtual colonoscopy,” and genetic testing of feces that identifies the genetic changes common in adenomas and CRC.³² However, abnormalities found with either of these two tests need to be followed up with colonoscopy.

CRC screening tests are widely available through providers in Maryland. Medicare Part B pays for screening by FOBT annually, for flexible sigmoidoscopy every 48 months, and for colonoscopy once every 24 months if risk is high and once every 10 years (but not within 48 months of a flexible sigmoidoscopy) for those at average risk. A barium enema can be substituted for either of the endoscopy procedures.³³ For Medicare, the client pays 20% of the Medicare-approved amount after the deductible for colonoscopy and 25% of the Medicare-approved amount for sigmoidoscopy if it is done in a hospital’s outpatient department. Maryland

Medical Assistance also covers the cost of screening ordered by a provider. Maryland law (effective June 30, 2001) mandates that health care plans include coverage for CRC screening according to American Cancer Society guidelines.

Figure 9.7 shows the percent of Marylanders aged 50 and over who reported having had an FOBT test within the past two years and at least one colonoscopy or sigmoidoscopy in their lifetime. Both screening methods are increasing.^{34,35} In the Maryland Cancer Survey of 2002, 44.4% of respondents reported having had an FOBT in the past two years and 58.2% reported having at least one sigmoidoscopy or colonoscopy in their lifetime; 74.4% of respondents reported having been tested either by FOBT, flexible sigmoidoscopy, or colonoscopy at least once.³⁶ Minorities were less likely to have been tested. About 63% of the population 50 and over are considered “currently screened” according to the American Cancer Society’s guidelines (FOBT in the past year; sigmoidoscopy in the past five years; FOBT plus sigmoidoscopy, or colonoscopy, in the past 10 years).³⁷ Of the 25.6 % of people who reported never

Figure 9.8**Ideal Model for Colorectal Cancer Control: Groups Involved and Their Optimal Features**

Health Education and Promotion (Health Educators, Community Health Workers, Outreach Workers, Media)	Public	Target Population for CRC Screening*	Primary Care Providers (Internist, Family Physician, Gynecologist, Nurse Practitioner, Physician's Assistant, Allied Health staff)
Design new and implement new or existing health risk reduction and health promotion messages.	Have access to affordable, “good” diet.	Aware of need for screening; knows current recommendations.	Sensitive to patients of all races, ethnicities, national origins, cultures, and socioeconomic status.
Design and implement messages that are consistent.	Receive primary prevention messages: specific to CRC or general “Healthy Lifestyle” messages through multiple channels.	Motivated for screening; myths and fears dispelled.	Able to see non-English-speaking patients.
Use strategies and workers that are targeted to minorities; are culturally sensitive; and are of the same ethnicity/race/language.	Eat a “good” diet, exercise, don’t use tobacco products.	Arrive at informed decision to be screened and requests screening.	Understand importance of screening and knows current recommendations.
	Receive public information about disease, risk factors (including age), screening recommendations, and availability of programs for low income, uninsured residents, minority populations.	Have insurance or funding to pay for screening.	Decide on the “screening scheme” for the office practice.
	Participate in community-based participatory research (surveys, focus groups).		Determine referral sources.
			Take adequate history.
			Arrive at informed decision on best screening for the patient.
			Clear patient for needed procedures.
			Screen (FOBT, flex sig) and/or send to specialists for screening (colonoscopy, DCBE).
			Develop FOBT in office or in reference lab.
			Inform patient of results and provides appropriate recommendations.
			Have reminder/recall/tickler system(s).
			Receive payment from insurance or other funding source to pay for consult and screening.

Specialists <i>(Gastroenterologist, Surgeon, Radiologist, Pathologist)</i>	Treatment Team <i>(Surgeon, Oncologist, Radiation Oncologist, Case Manager, Patient Navigator, Social Worker, Home care, Hospice)</i>	Researchers <i>(Basic research, translational research, community-based participatory research, and provider surveys)</i>
Accessible in sufficient numbers in each jurisdiction to perform needed procedures.	Sensitive to patients of all races, ethnicities, national origins, cultures, and socioeconomic status.	Focus research on: basic science of CRC, primary prevention and chemoprevention of CRC, patient and provider behavior change, new screening tests and their acceptability, and treatment of CRC.
Sensitive to patients of all races, ethnicities, national origins, cultures, and socioeconomic status.	Able to see non-English-speaking patients.	
Able to see non-English-speaking patients.	Guide patient through system overcoming barriers of language, understanding, transportation, form completion, application for insurance, etc.	
Perform sigmoidoscopy, colonoscopy, double contrast barium enema as optimal screening and/or diagnostic procedure(s).	Remove tumor; stage cancer, as appropriate.	
Perform additional biopsies or procedures at time of colonoscopy to remove adenomatous polyps and/or cancers.	Know best treatment.	
Send biopsies to pathologist.	Treat with most appropriate therapy.	
Read by pathologist and report results to referring doctor.	Refer patients for clinical trials, as appropriate.	
Inform patient and/or provider/health department of results and recommendations.	Provide follow-up care as needed.	
Receive payment from insurance or other funding source to pay for consult and testing.	Receive payment from insurance or other funding source to pay for consult and treatment services.	

*Target population for CRC screening includes all people aged 50 years and older and people of any age with increased risk, i.e., genetic syndrome; family or personal history of adenomatous polyps or CRC; personal history of inflammatory bowel disease; or ovarian or endometrial cancer.
Source: Developed by the Colorectal Cancer Committee of the MCCC.

having been screened for CRC, 87.9% reported having had a physical examination in a provider's office within the preceding two years.³⁸ Therefore, CRC screening opportunities were missed.

Ideal Model for Colorectal Cancer Control

Figure 9.8 shows the Ideal Model for Colorectal Cancer Control, detailing primary, secondary, and tertiary prevention. Central to this model is screening those who are 50 years and older and those of any age who are at increased risk (i.e. significant family history/personal history of colorectal cancer or adenomatous polyps, or a personal history of inflammatory bowel disease [ulcerative colitis or Crohn's colitis], or endometrial or ovarian cancer). Health education and promotion, community-based participatory research, basic colorectal cancer research, the availability of screening, and payment for outreach and health care must be combined to promote and support colorectal cancer screening. Primary care providers (internists, family physicians, and gynecologists) play a key role in the Ideal Model by recommending and referring patients for screening and by helping to change patient attitudes and behaviors in a culturally sensitive manner.

Barriers to Colorectal Cancer Screening

The Colorectal Cancer Committee identified the following barriers to screening:

Patient issues

- Lack of knowledge about CRC and screening recommendations; inconsistent messages about screening
- Lack of health insurance or a primary medical provider
- Mistrust of the health care system
- Confusion between various colonic "treatments" available over the counter (e.g., enemas, laxatives, nutrition products) and CRC screening
- Fear of knowing the results of screening
- Fear of the procedure(s)
- Lack of transportation, inability to take time off from work for screening, and other practical barriers

- Misconception that cancer is a uniformly fatal diagnosis and that screening is therefore not useful

Provider issues

- Confusion by providers over which screening strategy to recommend
- Lack of knowledge or confusion about persons who carry "increased risk" for colorectal cancer
- Lack of consistent messages by providers to patients about screening recommendations and follow-up
- Lack of providers who do colonoscopy and sigmoidoscopy
- Language and cultural barriers in provider offices
- Lack of providers, especially providers who will see low-income clients or clients who have Medical Assistance

Other issues

- Not all patients who have health insurance coverage for CRC screening are getting screened
- Health insurance, including Medicare, may not fully cover the CRC screening method chosen by the doctor and patient
- Insufficient funding for screening those who are low-income and un- or underinsured, especially in Baltimore City
- Funding is not available to pay for diagnosis and treatment for all people with colorectal cancer who have no health insurance

Current Efforts

Maryland Cigarette Restitution Funds were awarded to state counties in fiscal year 2001 for public health cancer prevention programs, and to the University of Maryland Medical Systems and the Johns Hopkins Institutions for Baltimore City. With this new funding, the 23 counties (excluding Baltimore City) focused on colorectal cancer with two goals: to decrease mortality and to reduce racial disparities. Locally controlled programs, designed in conjunction with their local community health coalition, began outreach and education for all residents and started CRC screening for those who met local income and insurance eligibility guidelines. Programs reported data to the DHMH Internet-based education database and submitted client screening data report forms.

By March 24, 2003, during the first 27 months of the program, local programs hired staff and contracted with numerous community-based and faith-based organizations. Together they provided CRC direct education or outreach to over 120,000 residents, 5,000 health care providers, and 500 trainers. Additionally, Marylanders were informed about CRC and screening through television, radio, newspapers, public service announcements, distribution of printed materials, billboards, and health fairs, among other media.

By January 14, 2004, over 11,000 Marylanders had been screened for CRC through the CRF program. Some local programs performed fecal occult blood tests. In the first two years of the program 6,791 residents of any income or insurance status were tested with FOBT and 9% were positive. For low-income, uninsured, or underinsured residents, the programs contracted with providers and paid for 113 sigmoidoscopies and 4,238 colonoscopies. 43% of those screened were racial and/or ethnic minorities. Adenomatous polyps were found on 832 (19.6%) of these colonoscopies and 54 cases of CRC were identified. Screening in the private sector also increased however, and local programs reported difficulty in enrolling men into screening.

In addition to the CRF programs in Maryland, a number of national educational efforts have begun. The federal Centers for Disease Control and Prevention (CDC), with its partner, the Center for Medicare and Medicaid Services (CMS), launched its Screen for Life program in March 1999 that focused on CRC.³⁹ The American Cancer Society launched its Ambassador and Ally programs targeting CRC screening, and in 2002 initiated its "Polyp Man" advertising campaign aimed to extend the "get tested for colon cancer" message. In addition to the ads, the program includes public education, clinical peer-to-peer communication, and community-based outreach activities. In Baltimore City, the American Cancer Society funded a demonstration project entitled East Baltimore's Bridge to Better Health that sought to gain a better understanding of the barriers that have contributed to higher incidence and mortality from cancer, in particular colorectal cancer, and collaborate with residents to develop strategies to overcome them. As a result of this initiative, Baltimore City residents have developed targeted educational messages, presentations, and materials in order to increase the number of people who are aware of, and utilize, available screening opportunities. Finally, the Cancer Research and Prevention Foundation has declared March as National Colorectal Cancer Awareness Month.

Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁴⁰ related to colorectal cancer:

Objective:

Reduce the colorectal cancer death rate to 13.9 per 100,000 population.

The U.S. baseline was 21.1 per 100,000 in 1998 (age-adjusted to the 2000 U.S. standard population).

Objective:

Increase the proportion of adults who receive a colorectal cancer screening examination:

- Increase the proportion of adults aged 50 years and older who have received a fecal occult blood test (FOBT) within the preceding 2 years to at least 50%.

The U.S. baseline was 35% in 1998 (age-adjusted to the 2000 standard population).

- Increase the proportion of adults age 50 years and older who have ever received a sigmoidoscopy or colonoscopy to at least 50%.

The U.S. baseline was 37% in 1998 (age-adjusted to the 2000 standard population).



Colorectal Cancer Goals, Objectives, and Strategies

Goals:

Reduce colorectal cancer mortality.

Reduce disparities in the incidence and mortality of colorectal cancer.

Targets for Change

By 2008, reduce the colorectal cancer mortality to a rate of no more than 20.8 per 100,000 persons in Maryland.

The Maryland baseline was 23.9 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Division of Health Statistics.

By 2008, decrease the percentage of Marylanders aged 50 and over who have never been screened for CRC to 15% or less.

The Maryland baseline was 25.6% in 2002.

Source: Maryland Cancer Survey.

By 2008, increase the percentage of Marylanders aged 50 and over who are up to date with screening (per ACS guidelines) to 73% or more.

The Maryland baseline was 63% in 2002.

Source: Maryland Cancer Survey.

By 2008, increase the percentage of Marylanders aged 50 and over who have been screened with either colonoscopy in the past 10 years or FOBT in the past year, plus flexible sigmoidoscopy in the past 5 years, to 57% or more.

The Maryland baseline was 47% in 2002.

Source: Maryland Cancer Survey.

Objective 1:

Increase the rate of screening for colorectal cancer of those aged 50 and older by increasing the public's knowledge of colorectal cancer risk factors, symptoms, screening recommendations, and options.

Strategies:

1. Develop "appropriate" messages and use appropriate educational channels for CRC screening recommendations. Messages should be available in various languages and should reach both sexes those of different racial, ethnic, and cultural backgrounds, and those with varying literacy levels.
2. Specifically target these messages to people aged 50 and older and to those at increased risk (i.e. those with a family history of CRC or adenomatous polyps in first degree relatives and those with a personal history of inflammatory bowel disease, endometrial cancer, or ovarian cancer).
3. Disseminate information about the availability of insurance coverage for CRC screening.
4. Educate and encourage the public to ask their health care providers about CRC screening and to ask their health insurers about coverage for such screening.
5. Use role models, cancer survivors, community groups, and people who have been screened to reach target audiences.
6. Evaluate the effectiveness of educational messages.
7. Measure the public's knowledge, attitudes, beliefs, and practices through the Maryland Cancer Survey and BRFSS (e.g., by adding/modifying questions as needed), focus groups, surveys of outreach workers, etc.

**Objective 2:**

Clarify myths and dispel fears about colorectal cancer related to appropriate screening and prevention methods.

Strategies:

1. Develop a committee to focus on education and information that will explore myths, perceptions, and facts surrounding CRC, and methods to dispel myths.
2. Support educational messages that dispel myths identified in focus groups or by outreach workers.
3. Use role models, cancer survivors, community groups, and people who have been screened to reach target audiences.
4. Establish “Patient Navigators” in community-based organizations to help dispel myths, give factual information, and overcome language, literacy, and cultural barriers.

Objective 3:

Increase the knowledge of primary care providers (including family physicians, internists, and gynecologists) of appropriate colorectal cancer screening recommendations, and increase the proportion of providers who recommend or provide screening for colorectal cancer.

Strategies:

1. Examine the current knowledge, attitudes, beliefs, and practices of providers.
2. Support collaboration among community organizations and programs to have one consistent message regarding screening.
3. Develop, promote, and evaluate appropriate messages regarding CRC screening recommendations for providers to share with their patients. For example:

- Discuss CRC screening with every patient aged 50 years and older and those at risk.
- Discuss available screening methods.
- Support colonoscopy as the method of choice for all who have no identified contraindications.
- Discuss informed consent when discussing screening.
- Make information accessible to those with low literacy levels and those with cultural and linguistic barriers.
- 4. Offer continuing medical education (CME) credits for education on CRC.
- 5. Discuss CRC at MedChi and other medical and nursing association meetings and conferences.
- 6. Develop a risk assessment tool to help providers and patients choose the most appropriate screening test.
- 7. Develop CRC screening reminder systems for provider offices.
- 8. Develop communication formats to convey the message and the meaning of informed decision-making.
- 9. Use role models or real-life examples of how practices have increased screening rates among their clients.
- 10. Encourage providers to volunteer as “test cases” for record review to monitor their implementation of CRC screening.
- 11. Monitor providers by adding CRC screening as a HEDIS (Health Plan Employer Data and Information Set) measure.

**Objective 4:**

Increase the trust of the public in the health care system.

Strategies:

1. Involve community groups to spread the message about the importance of early screening.
2. Use role models, cancer survivors, and outreach workers to target minority or other underserved populations for screening. Utilize people who were successfully screened in this effort.
3. Use members of the community in planning and implementing CRC education and screening programs.
4. Hold a public forum for health care providers, insurers, and the community regarding CRC.
5. Involve the clergy, Ministerial Alliance, community-based organizations, and provider groups, such as the Monumental Medical Society, in developing and delivering educational messages about CRC.

Objective 5:

Promote health insurance coverage for colorectal cancer screening methods that are appropriate for each individual.

Strategies:

1. Amend Maryland's current legislation to make it explicit that insurers should cover the screening procedure that a health care provider orders.
2. Distribute information on the cost-benefit of screening to CEOs of health insurance agencies, legislators, and decisionmakers of benefits packages for large groups.
3. Encourage patients to advocate for insurance coverage of CRC screening when negotiating for health benefits (e.g., when union contracts are negotiated).
4. Work to encourage and support top management and businesses that provide screening coverage as part of health insurance packages.

Objective 6:

Overcome barriers to screening, including difficult pre-procedure colonic preparation, transportation issues, scheduling and timing issues including conflict with work schedules, living alone, etc.

Strategies:

1. Have patient advocates and case managers within local health departments, community-based organizations, churches, and hospitals assist with overcoming barriers.
2. Provide flexible scheduling for colonoscopies such as after-hours clinics or weekend hours.

**Objective 7:**

Ensure that patients with insurance coverage for colorectal cancer screening are screened.

Strategies:

1. Encourage companies/employers to educate workers on the importance of screening and the availability of CRC screening coverage under their health care plan.
2. Disseminate messages to the public regarding the importance of understanding their medical insurance coverage for CRC screening.

Objective 8:

Increase available funding to pay for diagnosis and treatment for all who are screened and found to need additional care.

Strategies:

1. Explore the feasibility of initiating and funding a statewide program to pay for diagnosis and treatment of CRC, similar to the Breast and Cervical Cancer Diagnosis and Treatment Program.

Objective 9:

Overcome language, literacy, and cultural barriers in health care providers' offices.

Strategies:

1. Hold cultural competency training and develop educational materials for providers.
2. Educate providers regarding cultural diversity, literacy, and cultural sensitivity as part of the knowledge base for informed consent.
3. Hire advocates and case managers in community-based organizations.
4. Hire multilingual outreach workers in all medical facilities.
5. Have providers reimbursed for time spent overcoming language and cultural barriers (e.g., payment for Language Line).

Objective 10:

Increase funding for colorectal cancer screening among uninsured, low-income Maryland residents, especially in Baltimore City.

Strategies:

1. Maintain funding from the Cigarette Restitution Fund for the jurisdictions currently funded.
2. Initiate a CRC screening program in Baltimore City and secure more funding for screening uninsured residents.

**Objective 11:**

Ensure that there are sufficient providers to perform colonoscopy and/or sigmoidoscopy for all who require the procedures in Maryland.

Strategies:

1. Assess the degree to which colonoscopy and sigmoidoscopy availability is a problem in Maryland.
2. Have providers perform colonoscopy or flexible sigmoidoscopy in alternative settings such as a mobile unit (Scope-mobile) or free-standing medical centers.
3. Set minimum standards for the number of sigmoidoscopies or colonoscopies that a provider needs to perform each year.
4. Examine the role of nurse practitioners in providing exams, including colonoscopy and flexible sigmoidoscopy.

Objective 12:

Ensure that there are sufficient providers who can perform initial physicals and clearance examinations for the uninsured, accept low-income clients and clients with Medicare and Medical Assistance, and have flexible hours necessary to working patients.

Strategies:

1. Examine providers' attitudes and practices.
2. Determine the current availability of night and weekend hours to patients.
3. Examine the role of nurse practitioners in providing exams, including colonoscopy and flexible sigmoidoscopy.

Objective 13:

Communicate the importance of primary prevention of colorectal cancer through healthy lifestyles. (Please refer to the Goals, Objectives, and Strategies in chapter 6 on diet and physical activity.)

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CHAPTER 10

BREAST CANCER

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BREAST CANCER

Breast cancer is the most common type of cancer in women (excluding basal and squamous skin cancers) and the second leading cause of cancer death in women. It is estimated that one in nine women will be diagnosed with breast cancer during their lifetime. Although breast cancer is thought of as a woman's disease, approximately 1% of all breast cancers are diagnosed in men every year.¹

A breast tumor is formed when DNA in the cells of the breast tissues are genetically altered and begin uncontrolled growth and replication. Not all breast tumors are malignant. Benign tumors are not cancerous, will not spread to other parts of the body, and are not life threatening. Malignant or cancerous breast tumors are capable of invading and destroying adjacent tissues and spreading to distant parts of the body and are life threatening.^{2,3}

There are several types of breast cancer: ductal carcinoma, lobular carcinoma, inflammatory breast cancer, and Paget's disease. Ductal carcinoma starts in the lining of the milk ducts and accounts for 86% of all breast cancers. Medullary, tubular, adenocystic, and papillary cancers are all types of ductal carcinoma.

Lobular carcinoma originates in the lobules where breast milk is produced and accounts for 12% of all breast cancers.^{4,5}

Both ductal and lobular carcinoma can be further categorized as "in situ" (noninvasive) or "infiltrating" (invasive). Infiltrating cancers grow outside of the lobules or ducts where they originated, invading surrounding tissue. When breast cancer spreads to other parts of the body it is classified as metastatic. Some cases of ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS) may eventually become invasive.⁶ Women who have had invasive cancer, DCIS, or LCIS are at increased risk of developing a second breast cancer.⁷

Inflammatory breast cancer is often mistaken for an infection. The first symptoms of inflammatory breast cancer are redness and warmth of the breast skin, with or without a distinct lump. In inflammatory breast cancer, cancer cells are found in the lymph vessels of the skin, blocking drainage of fluids from the skin. Inflammatory breast cancer accounts for 2%–4% of all breast cancers and usually has a poorer outcome than other types of breast cancer.⁸

Paget's disease involves the nipple. Often mistaken for eczema, the nipple appears to be scaly and itchy. Paget's disease may be associated with ductal carcinoma, and it may or may not invade the tissues under the nipple.⁹

Risk Factors

Certain risk factors may increase the chance of developing breast cancer including the following:

Table 10.1
Female Breast Cancer Incidence and Mortality Rates
By Race in Maryland and the United States, 1999

Incidence 1999	Total	Whites	Blacks	Other
New Cases (#)	3,714	2,752	822	96
Incidence Rate	137.0	139.5	127.7	92.8
U.S. SEER Rate	139.1	143.0	123.9	NA
Mortality 1999	Total	Whites	Blacks	Other
MD Deaths (#)	782	567	211	**
MD Mortality Rate	28.5	27.4	35.5	**
U.S. Mortality Rate	27.0	26.3	35.8	NA

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

**Rates based on cells with 25 or fewer non-zero cases are not presented per DHMH/MCR Data Use Policy.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

Age

The main risk factor for developing breast cancer is increasing age.

Hormonal Factors

Women with early onset of menstruation, late age at first birth, and/or late menopause are more likely to develop breast cancer. These factors suggest circulating hormone levels contribute to the risk of getting breast cancer.

Personal History

Women who have had proliferating forms of benign breast disease such as atypical hyperplasia and lobular carcinoma in situ are at increased risk of developing breast cancer. Women who have had ductal carcinoma in situ or a previous invasive breast cancer are also at increased risk of developing a second breast cancer.

Family History

Women with a family history of breast cancer are at increased risk of developing breast cancer, especially women whose mother or sister had breast cancer. About 5% to 10% of women who develop breast cancer have a strong inherited predisposition to breast cancer. Mutations in two genes (BRCA1 and BRCA2) explain about half of these inherited forms of breast cancer. Women with mutations in these genes are at risk for other cancers as well, especially ovarian cancer. Certain ethnic groups, such as individuals of Ashkenazi Jewish descent, have a higher prevalence of mutations

in these genes compared to the general population. The prevalence of mutations in BRCA1 and BRCA2 among Ashkenazi women is approximately 1.5% to 2.0%. Genetic testing can be done to determine if individuals carry mutations in these genes.

Radiation Exposure

Exposure to ionizing radiation is a risk factor for developing breast cancer, particularly when exposure occurs in adolescence or early adulthood. For example, women who were treated with radiation for Hodgkin's disease have a higher risk of developing breast cancer.

Alcohol

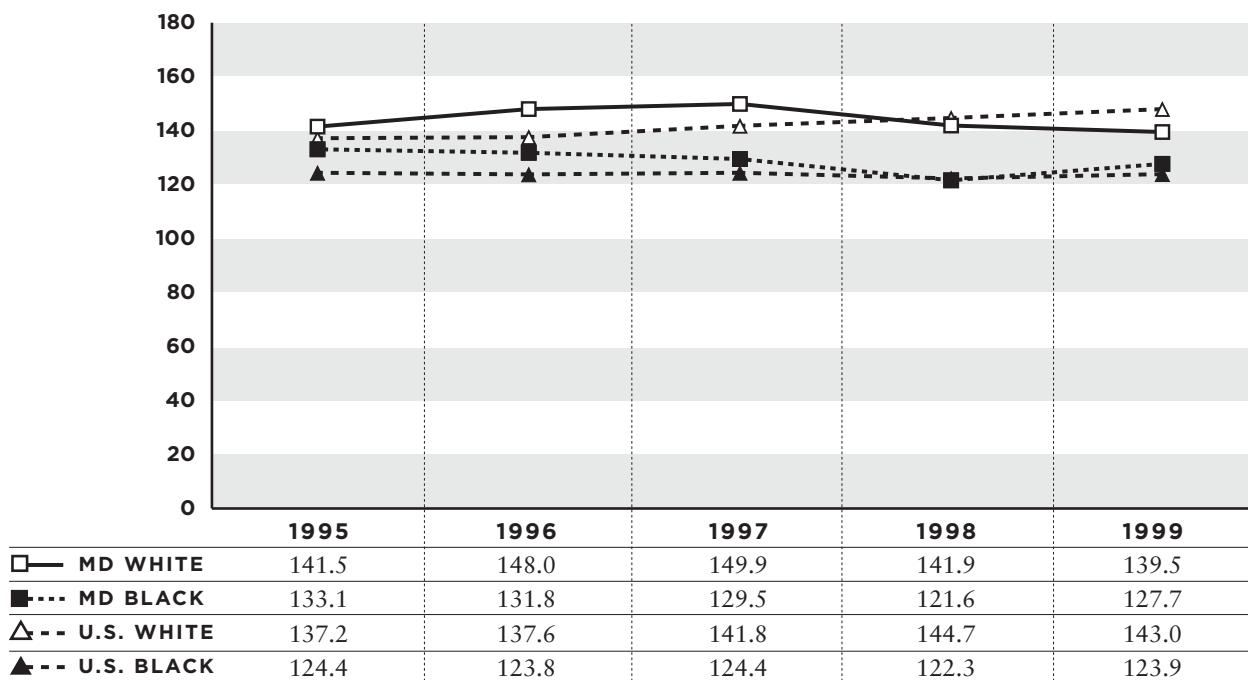
Alcohol intake is associated with a small increased risk of breast cancer. Studies have shown that one to two drinks daily are associated with an increased risk of breast cancer.

Diet and Obesity

Obesity is a risk factor for breast cancer, especially after menopause.¹⁰ An ongoing trial, the Women's Health Initiative, has a low-fat dietary intervention arm that will assess the impact of a low-fat diet on cancer, heart disease, and other health outcomes. Studies suggest that exercise, particularly among young adults, may be associated with a reduced breast cancer risk.¹¹

Hormonal Therapy

Postmenopausal hormone replacement therapy with estrogen and/or a combination of estrogen and prog-

Figure 10.1**Breast Cancer Incidence by Race in Maryland and the United States, 1995-1999**

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

estin is associated with an increased risk of breast cancer.^{12,13} Increased risk of breast cancer is observed after about five years of use. The risk may be higher with combined estrogen and progestin therapy than with estrogen alone. Oral contraceptive use is not associated with a long-term increased risk of breast cancer.

Burden of Breast Cancer in Maryland

Breast cancer is the most commonly diagnosed cancer among women, and accounts for about 32% of all cancers diagnosed among women in Maryland.¹⁴ Data from the Maryland Cancer Registry (MCR) show that 3,714 women were diagnosed with breast cancer in 1999 (Table 10.1). The overall age-adjusted breast cancer incidence rate for Maryland in 1999 was 137.0 per 100,000 women. Maryland's overall age-adjusted breast cancer incidence rate as well as the specific rates for white and black women are similar to the SEER rates for the nation (Figure 10.1). Since 1992, when the MCR first compiled Maryland cancer incidence data, breast cancer rates have shown year-to-year fluctuations but no clear trend has emerged.

The risk of breast cancer increases with age, with incidence

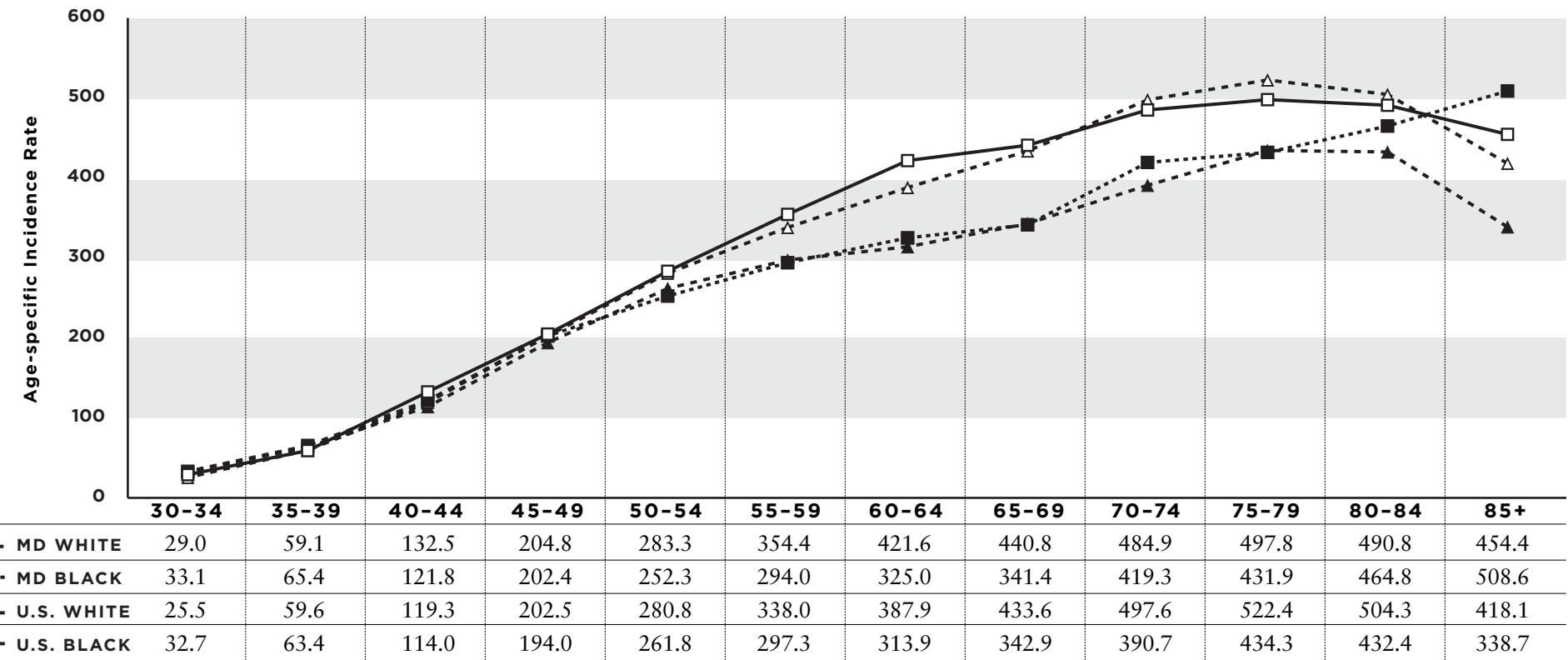
rates increasing with age for both white and black women. However, white women have consistently higher age-specific incidence rates than black women (Figure 10.2).

Although black women have lower breast cancer incidence rates than white women, black women have a disproportionate amount of late stage breast cancer. Between 1992 and 1997, 6.7% of the breast cancers diagnosed among blacks in Maryland were distant stage and 51.7% were local stage, compared to 4.2% distant stage and 61.6% local stage for whites (Figure 10.3). SEER data show the same patterns.

The Maryland Cancer Registry does not currently calculate survival rates, but SEER data show that the overall five-year survival rate for breast cancer between 1992 and 1998 was 86%. For white women the five-year survival rate was 87% and for black women it was 73%. Black women have lower five-year survival rates than white women for each stage of breast cancer and each age group. The five-year survival rate for distant stage breast cancer is 24% for white women and 15% for black women and the five-year survival rate for local stage breast cancer is 97% for white women and 89% for black women.¹⁵

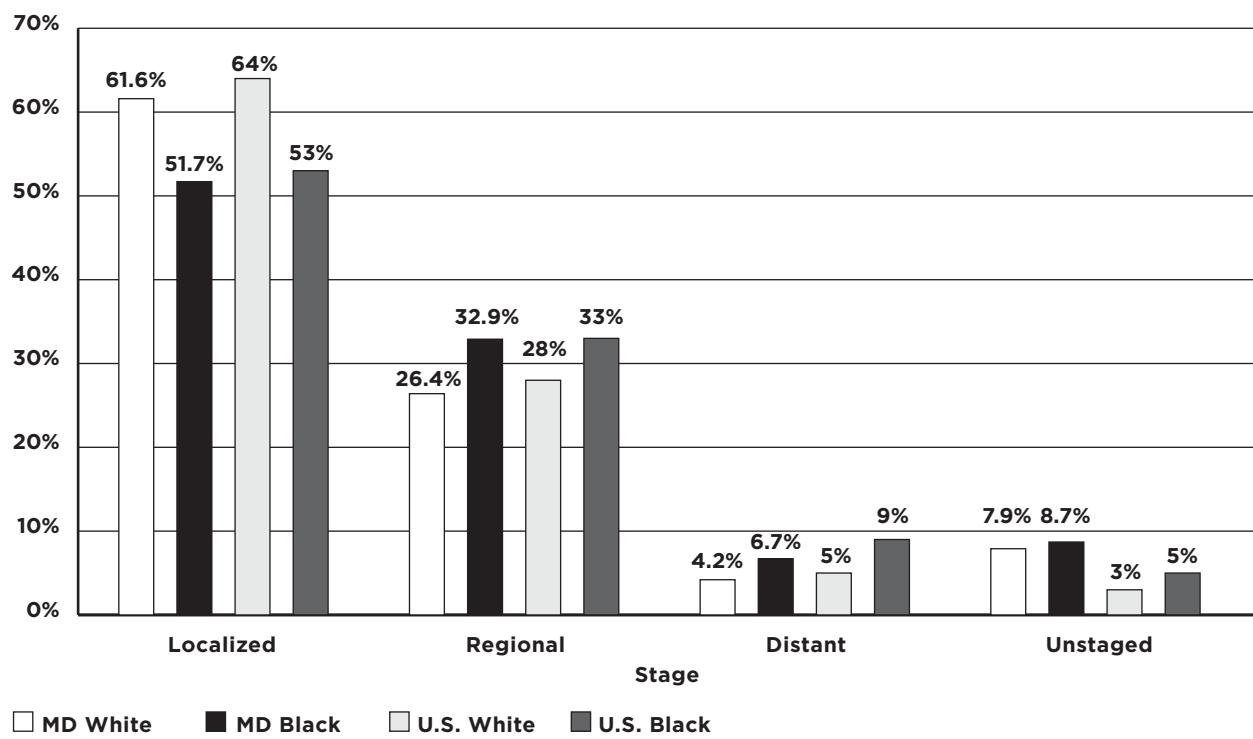
Breast cancer is the second leading cause of cancer

Figure 10.2
Breast Cancer Age-Specific Incidence Rates by Race in Maryland and the United States, 1995–1999



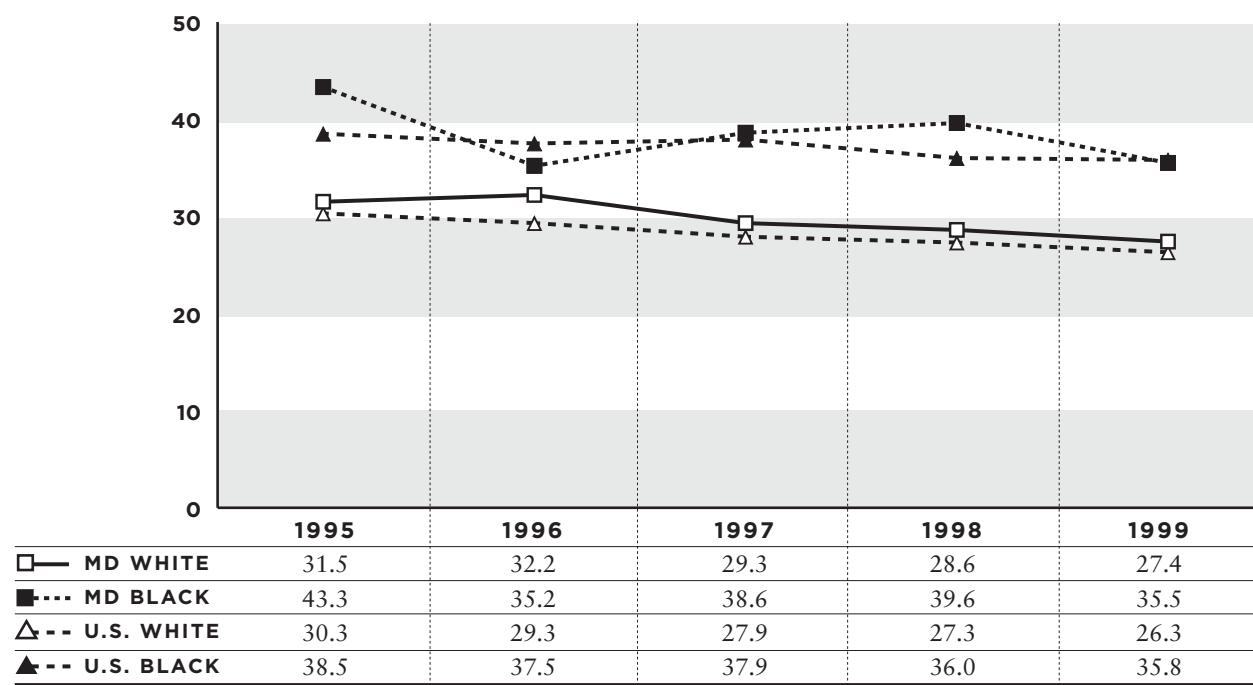
Rates are per 100,000 and age-adjusted to the 2000 U.S. population.
Source: Maryland Cancer Registry, 1995–1999; SEER, National Cancer Institute, 1995–1999.

Figure 10.3
**Breast Cancer Stage of Disease at Diagnosis by Race
in Maryland and the United States, 1992-1997**



Source: Maryland Cancer Registry, 1992-1997; SEER, National Cancer Institute, 1992-1997.

Figure 10.4
Breast Cancer Mortality Rates by Race in Maryland and the United States, 1995-1999

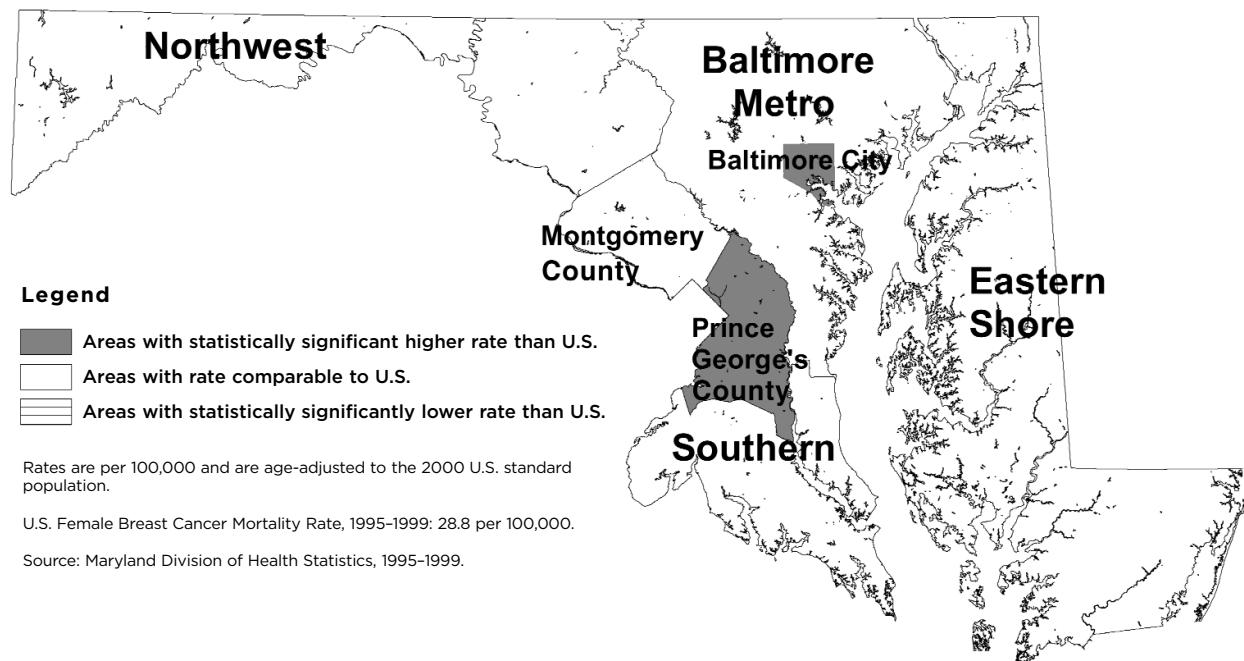


Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Division of Health Statistics, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 10.5

**Maryland Female Breast Cancer Mortality Rates by Geographical Area:
A Comparison to Rates in the United States, 1995-1999**



death for women in Maryland,¹⁶ accounting for about 17% of all cancer deaths among women in Maryland.¹⁷ In 1999, there were 782 Maryland deaths from breast cancer. Maryland's female age-adjusted breast cancer mortality rate was 28.5 per 100,000 in 1999, which is significantly higher than the national rate of 27.0 per 100,000 (Table 10.1). Historically, Maryland has had high breast cancer mortality rates and currently has the fifth highest breast cancer mortality rate in the nation.¹⁸ The overall decrease in breast cancer mortality is due to decreases in breast cancer rates among white women. The 1999 Maryland age-adjusted breast cancer mortality rate for black women was 35.5 per 100,000 while for white women it was 27.4 per 100,000.

Maryland's mortality rate has been declining since 1995 (Figure 10.4). Black women have significantly higher breast cancer mortality rates compared to white women, both nationally and in Maryland.¹⁹ Breast cancer mortality rates for black women have remained high while rates for white women have declined. Since Maryland has a larger proportion of African Americans compared to the nation, the breast cancer mortality rate will likely remain high in Maryland until the gap between white and black breast cancer mortality rates narrows.

Baltimore City and Prince George's County have significantly higher breast cancer mortality rates than the United States (Figure 10.5). These two jurisdictions have a majority African-American population. All other jurisdictions have breast cancer mortality rates that are comparable to U.S. rates.

As stated, breast cancer mortality rates for black women are higher than those for white women in Maryland and the United States. This trend also applies to all age groups. Figure 10.6 examines these rates from ages 35 to 85.

Disparities

- Although black women have a lower incidence of breast cancer, they have a higher breast cancer mortality rate.
- Black women have a greater proportion of late stage breast cancer than white women.
- For each breast cancer stage and age group, black women have lower five-year survival rates than white women.

Primary Prevention

Breast cancer prevention includes a broad range of activities, from lifestyle efforts such as maintaining an ideal weight, to consideration of chemoprevention or prophylactic surgery for specific high-risk individuals. Obesity is a risk factor for breast cancer, especially after menopause,²⁰ and rates of being overweight and obese have dramatically increased in the state over the past 10 years. Approximately 20% of individuals in Maryland are obese and over half are overweight. Reducing and preventing obesity throughout adulthood is a high priority as it would help reduce the risk of breast cancer while improving general health, as obesity is a major cause of diabetes, heart disease and other cancers. Interventions to prevent and reduce obesity would include increasing low physical activity levels, which are also associated with the risk of breast cancer. These interventions would have a far-reaching impact for the entire population.

A review and meta-analysis of data from 47 studies concluded that breast-feeding is protective against breast cancer.²¹ There is an approximate 4.3% decrease in the risk of developing breast cancer for each year of breast-feeding. The protective effect of breast-feeding was found to be separate from the protective effect of childbearing. Each birth reduces breast cancer risk by about 7%, independent of breast-feeding.

Women and their primary care providers should assess breast cancer risk and develop the most appropriate strategy to manage the risk.

Genetic testing may be useful for women making decisions regarding chemoprevention, prophylactic surgery, or treatment (e.g., lumpectomy vs. mastectomy). Genetic counseling programs are located in the Baltimore and Washington, D.C. areas but are less available for residents in Western Maryland or on the Eastern Shore.

A randomized controlled trial has shown that the drug tamoxifen reduces the risk of developing breast cancer by 50% in women who are at increased risk for the disease. Tamoxifen also reduces the risk of bone fractures. However, tamoxifen also has adverse effects including an increased risk of endometrial cancer, thrombotic events (deep venous thrombosis, pulmonary embolism, stroke), menopausal symptoms, and cataracts. Women at increased risk of breast cancer (at least a 1.67% five-year breast cancer risk) should be counseled regarding the potential risks and benefits of taking tamoxifen for chemoprevention.^{22,23}

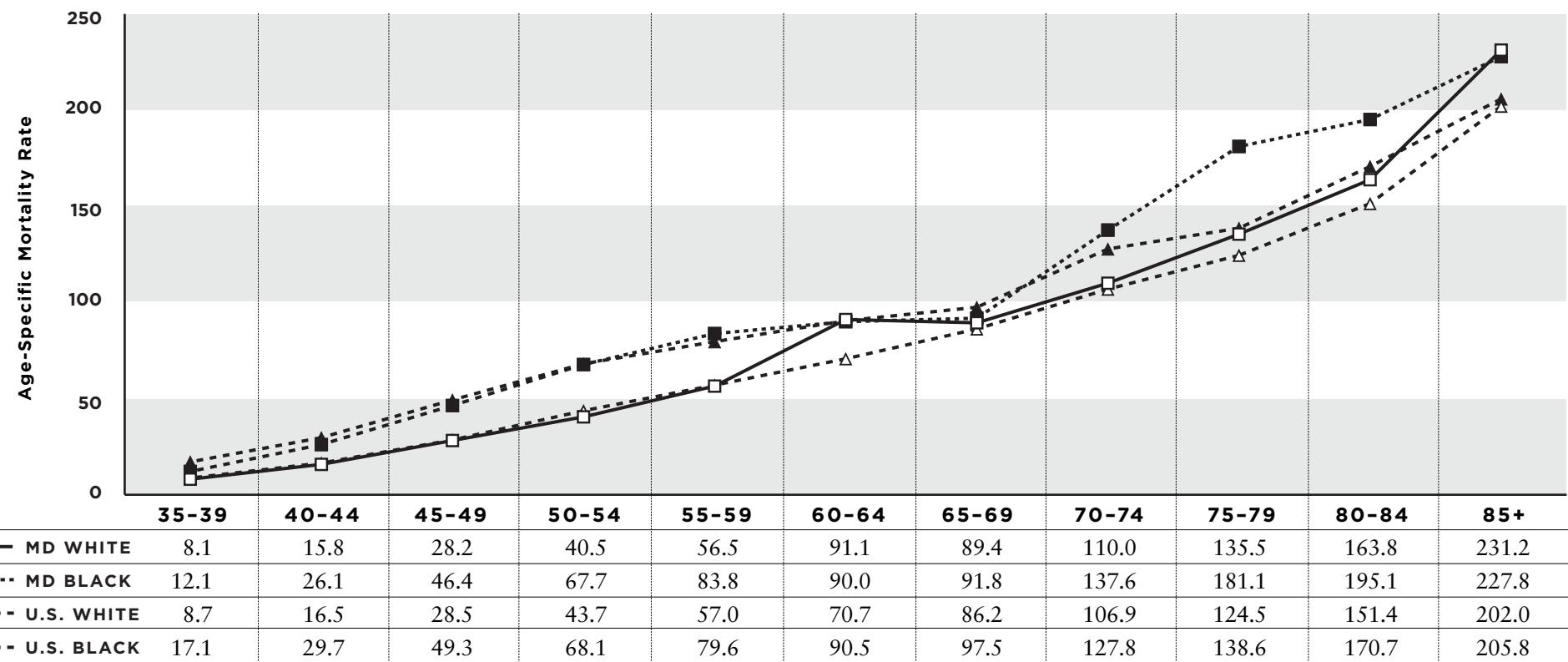
Raloxifene is a drug similar to Tamoxifen, but one that does not have the same estrogen-like effect on the uterus. Studies among women at low risk of developing breast cancer (i.e. women with osteoporosis) have shown a decreased risk of developing breast cancer with this drug treatment. Raloxifene has not been tested in women at increased risk of developing breast cancer. Raloxifene is approved for use only among post-menopausal women. A clinical trial (STAR) comparing the efficacy of tamoxifen and raloxifene in reducing the risk of breast cancer among high-risk post-menopausal women is currently underway.²⁴

Aromatase inhibitors prevent production of estrogen among post-menopausal women by blocking the action of the enzyme aromatase, a compound necessary for estrogen synthesis.²⁵ This class of drugs has not been tested as preventive agents. The evidence that they may reduce the occurrence of new breast cancer comes from a breast cancer treatment trial called ATAC (Arimidex, Tamoxifen, Alone or in Combination). The study showed that anastrozole (an aromatase inhibitor) alone reduced the incidence of new breast cancer among women with a history of hormone-receptor positive breast cancer compared to tamoxifen.^{26,27,28} Side effects occur at about the same rate as tamoxifen but are different than tamoxifen's, with fewer occurrences of hot flashes, vaginal bleeding, weight gain, strokes, and blood clots. However, aromatase inhibitors were associated with higher rates of muscular skeletal complaints and fractures.^{29,30} A prevention trial in Europe (IBIS2) is planning to test the efficacy of an aromatase inhibitor as a chemopreventive agent among high risk women.

The U.S. Preventive Services Task Force (USPSTF) recommends that clinicians discuss chemoprevention with women at high risk for breast cancer and at low risk for adverse effects of chemoprevention. Clinicians should inform patients of the potential benefits and harms of chemoprevention. The USPSTF recommends against routine use of tamoxifen or raloxifene for the primary prevention of breast cancer for women at low or average risk.³¹

Bilateral prophylactic mastectomy is associated with a reduction in the risk of breast cancer by as much as 90% among women with an increased risk of breast cancer due to a strong family history of breast cancer. Because of the physical and psychological effects of bilateral mastectomy and the irreversibility of the procedure, decisions regarding this option must be care-

Figure 10.6
Breast Cancer Age-Specific Mortality Rates by Race in Maryland and the United States, 1995-1999



Rates are per 100,000 and are age-adjusted to the 2000 U.S. population.

Source: Maryland Division of Health Statistics, 1995-1999; SEER, National Cancer Institute, 1995-1999.

fully considered on an individual basis in association with risk assessment and counseling.³²

Screening and Evidence of Benefit

Mammography and clinical breast examination are the primary methods of screening for breast cancer. A mammogram is a special X-ray of the breast that can often find tumors that are too small to be felt. The ability of mammography to detect cancer depends on factors such as the size of the tumor, the age of the woman, breast density, and the skill of the radiologist.

Uncertainty in the degree of benefit from routine mammography has been raised because of design flaws in the randomized clinical trials. This emphasizes the need to develop better methods to detect breast cancer in its early stage to improve health outcomes. There is general consensus among medical organizations regarding breast cancer screening guidelines for women aged 40 and older. The majority of organizations recommended screening with mammography, with or without clinical breast examination, every one to two years for women aged 40 and older.

The USPSTF found fair evidence that mammography screening every 12–33 months significantly reduces mortality from breast cancer. Evidence is strongest for women aged 50–69, the age group generally included in screening trials. For women aged 40–49, the evidence that screening mammography reduces mortality from breast cancer is weaker, and the absolute benefit of mammography is smaller than it is for older women. Most studies indicate a mortality benefit for women undergoing mammography at ages 40–49, but the delay in observed benefit in women younger than 50 makes it difficult to determine the incremental benefit of beginning screening at age 40 rather than at age 50.³³

The absolute benefit is smaller because the incidence of breast cancer is lower among women in their 40s than it is among older women. The USPSTF concluded that the evidence is also generalizable to women aged 70 and older (who face a higher absolute risk for breast cancer) if their life expectancy is not compromised by co-morbid disease. The absolute probability of the benefits of regular mammography increase along a continuum with age, whereas the likelihood of harms from screening (false-positive results and unnecessary anxiety, biopsies, and cost) diminish from ages 40–70. The balance of benefits and potential harms, therefore,

grows more favorable as women age. The precise age at which the potential benefits of mammography justify the possible harms is a subjective choice. The USPSTF did not find sufficient evidence to specify the optimal screening interval for women aged 40–49.

During a clinical breast examination (CBE), the health care provider carefully feels the breasts and under the arms to check for lumps or other unusual changes. The USPSTF found that the evidence is insufficient to recommend for or against routine CBE alone to screen for breast cancer.³⁴ Several other organizations, including the American Cancer Society and the Susan G. Komen Breast Cancer Foundation, recommend a clinical breast examination every three years between the ages of 20 and 40 and an annual CBE after age 40.

When a woman examines her own breasts it is called breast self-examination (BSE). Many organizations such as the Susan G. Komen Breast Cancer Foundation recommend monthly breast self-examination beginning at age 20. The USPSTF found that the evidence is insufficient to recommend for or against teaching or performing routine breast self-examination.³⁵

Diagnostic Tools

The primary role of ultrasound is the evaluation of palpable or mammographically identified masses. A review of the literature and expert opinion by the European Group for Breast Cancer Screening concluded that there is little evidence to support the use of ultrasound in population breast cancer screening at any age.³⁶

Magnetic Resonance Imaging (MRI) has been used to evaluate palpable breast masses and to discriminate between cancer and scar tissue.³⁷ The use of MRI for the early detection of breast cancer is still under investigation.

Ductal lavage is a relatively new procedure used to collect and analyze breast ductal epithelial cells.^{38,39} It involves insertion of a catheter into the breast ducts surrounding the nipple and is used as a risk assessment tool to detect atypical cells. It is similar to, but more efficient than nipple aspiration, an open biopsy showing atypia, and four-quadrant needle aspiration, and probably confers the same increase in relative risk as these methods. The sensitivity and specificity of this procedure for detecting cancer or high-risk breast lesions are unknown as is the significance of finding atypical cells in the fluid. Until the risks and benefits of the procedure are established, ductal lavage should not

be considered for general population screening. Ductal lavage, however, may be useful as a risk assessment tool in tailoring a risk reduction program for individual high-risk patients if the procedure is shown to be valid and reliable.

Sentinel Lymph Node Biopsy (SLNB) is a recently developed surgical procedure that uses radiolabeled dye to locate the first lymph node, or groups of lymph nodes (sentinel node), to which cancer has likely spread. Prior to the use of SLNB, a woman with breast cancer would have an axillary node dissection, which is a more extensive dissection that removes many lymph nodes. Axillary node dissection results in an increased risk of lymphedema (a lifelong condition), limited range of motion (sometimes requiring physical therapy), and dyesthesia along the upper inner arm.

Results of the biopsy of sentinel nodes are highly predictive for the presence or absence of axillary node metastases.^{40,41,42,43,44,45,46} A sentinel node that is negative for malignant cells is indicative of negative axillary node involvement, and the patient may be spared the need for full axillary lymph node dissection.^{47,48,49,50,51,52} False negative rates range from about 2% to 11%.^{53,54,55,56} It is currently unclear whether removing lymph nodes improves survival, so missing positive nodes may result in the understaging of cancer rather than premature deaths.^{57,58,59} Current clinical trials sponsored by NCI are underway to determine whether sentinel node biopsy can replace axillary node dissection when sentinel nodes are negative and, when the nodes are positive, if survival is different for women receiving axillary node dissection compared to those who do not.^{60,61}

There is a large “learning curve” for performing sentinel node biopsy.^{62,63,64} The American Society of Breast Surgeons recommends that a surgeon perform at least 20 sentinel node procedures in conjunction with axillary dissection or at least 20 sentinel node procedures with mentoring by a credentialed sentinel node surgeon to minimize false negatives.⁶⁵

Mammography Screening Rates

Mammography screening rates⁶⁶ in Maryland and the U.S. have shown a steady increase.

The percent of Maryland women aged 40 and older reporting a mammogram within the previous two years

increased from 75% in 1990 to about 82% in 2000. Maryland's rates have been consistently higher than the national rates for women aged 40 and older reporting a mammogram within the previous two years; the national average was about 58% in 1990, increasing to 76% in 2000. Mammography screening rates are similar among white and black women in Maryland.

Screening Behaviors, Beliefs, and Barriers

In 1996, ten focus groups consisting of Maryland women over the age of 50 who did not obtain regular mammograms were conducted. The following were key findings:⁶⁷

- Most women understood the need for regular/preventive health care and medical check-ups, but were not meticulous about getting them unless they had a specific problem or illness.
- Nearly all women knew the term mammogram, understood the procedure, and had obtained at least one mammogram. None of the women had annual mammograms.
- Most women knew that regular mammograms were recommended, but some were not sure if “regular” meant every year, every two years, etc.
- The most common reason for not getting a mammogram was negative experiences by the respondents or their friends or family members, particularly the discomfort or pain caused by the procedure. Other barriers include the ability of a mammogram to accurately detect breast cancer, the cost of a mammogram for high- and low-income women, and fear of radiation.
- Participants could not identify a single motivating factor for getting a mammogram. Some said that if a friend or family member got a mammogram and was diagnosed with cancer and then encouraged the respondent to have a mammogram, they would be motivated. Some said their physician provided the motivation for their first mammogram, others said that repeated reminders from the doctor do them little or no good.
- Women get the greatest amount of health information from magazines in the popular press. African-American women in Baltimore mentioned churches as an important source of information. Participants preferred to get information from friends or family members rather than celebrities.

In a study comparing breast screening rates in three racial groups (black, Hispanic, and white women), the important predictors of the use of breast cancer screening procedures for each group were having had a routine examination in the past year, having seen an obstetrician, gynecologist, or other specialist during the last routine exam, and having more than a high school education.⁶⁸

Another study found that compliance with screening recommendations was greater among those women who received a reminder letter for mammography.⁶⁹ A physician reminder letter combined with telephone counseling from a health educator significantly increased women's use of mammograms in a low-income population in a managed care setting.⁷⁰

Compared to standard care, telephone counseling was more than twice as effective at increasing mammography adherence, and in-person counseling resulted in almost three times the mammography adherence. Both telephone and in-person counseling are successful in changing perceived susceptibility, knowledge, barriers, and benefits.⁷¹ Compared to standard care alone, telephone counseling promoted a significantly higher proportion of women having mammograms on schedule than did tailored print materials, but only after the first year of the intervention. Telephone counseling was more effective than tailored print materials at promoting the regular scheduling of screening among women who were did not adhere to a schedule the previous year.⁷²

Ideal Model for Breast Cancer Control

There are four main steps within the ideal breast cancer control process: Prevention, Early Detection, Treatment, and Survivorship (Figures 10.7–10.10). Each step in the model identifies the key actions that should be taken by the general public, patients, primary care providers, medical specialists, and medical institutions. The models also show areas where more research is needed. The overarching issues in each model are a need for cultural sensitivity throughout the process, the use of multidisciplinary teams, and the availability of state-of-the-art diagnosis and treatment options to be administered by trained providers for all patients regardless of income, race, geographic region, or ability to pay.

The members of the Breast Cancer Committee identified the following barriers to care in each of the steps

in the ideal breast cancer control process:

Prevention and Early Detection Gaps or Barriers

- The Maryland Breast and Cervical Cancer Program has enough funds to screen 10%–15% of uninsured or underinsured women in the state for breast cancer. There are significant numbers of women who are uninsured or underinsured who cannot afford breast cancer screening.
- Accessibility to screening services may be limited because of hours of operation, availability of public transportation, or a lack of knowledge among patients and providers about the availability of existing services, especially for the socioeconomically disadvantaged.
- Cultural and language barriers prevent women from seeking screening and treatment. Few hospitals and even fewer physicians have staff who are able to speak to patients in their native language and must resort to using family members or friends as translators.
- There is a lack of written material in languages other than English and Spanish, and there is a lack of written materials at a reading level that is easy for all patients to understand.
- There are an increasing number of providers who refuse Medicare or Medicaid patients because of limited reimbursement rates.
- There is limited participation in breast cancer prevention clinical trials.

Treatment Gaps or Barriers

- Not all women in the state are receiving optimum care. Use of needle biopsies, rather than excisional biopsies, as the first step after a suspicious mammogram needs to occur across all regions of the state. Patterns of care throughout the state need to be assessed and results of clinical trials need to be monitored to apply new treatment interventions. As a result, sentinel node biopsy may replace axillary lymph node dissection for many women.
- There is a lack of information about treatment options and programs to pay for certain components of treatment.
- There is a need for improvement in the coordination of care among the many physicians treat-

ing a woman with breast cancer. Patients being treated for breast cancer are under the care of several different physicians, including radiologists, surgeons, and oncologists, as well as their primary care provider.

- Funds available in the Breast and Cervical Cancer Diagnosis and Treatment Program are insufficient to serve all uninsured or underinsured women diagnosed with breast cancer in Maryland.
- Few patients are offered psychosocial support or evaluation and insurance carriers may limit access to psychologists and psychiatrists. Additionally, co-pays for counseling are usually greater than for other medical specialists. Publicly funded mental health clinics are underfunded, have limited hours and staff, and limited space for new patients.
- There is limited participation in breast cancer treatment clinical trials.

Survivorship Gaps or Barriers

- Patients and providers may lack knowledge about the long-term effects of breast cancer treatment. As the cohort of survivors who were treated with chemotherapy age, research into the long-term effects of chemotherapy and other treatments needs to be supported.
- Culturally sensitive materials regarding survivorship issues in languages other than English need to be developed and made available to the public.
- There is a lack of coordination of care among specialists and primary providers following treatment. This may result in important aspects of care being lost in the gaps.
- Fears of insurance discrimination and employment termination are real for women who have been diagnosed with breast cancer and women with a family history of breast cancer who wish to undergo genetic testing.
- There is a lack of support systems for breast cancer patients. Support systems allow breast cancer patients the opportunity to talk about their disease to others and can provide a wealth of practical information and emotional support. Support groups are lacking in many minority and rural communities. Where support groups do exist, accessibility may be limited due to a lack of transportation.
- There is a need for respite care programs and reimbursement for hospice care services.

Current Efforts in Maryland

The Maryland Department of Health and Mental Hygiene (DHMH) Breast and Cervical Cancer Program (BCCP) is a statewide program that provides breast and cervical cancer screening services to uninsured or underinsured, low-income (less than 250% of the federal poverty level) women 40–64 years of age. Across the state, the DHMH awards funds to each jurisdiction to coordinate the provision of breast and cervical cancer outreach, patient and public education, and screening, referral, follow-up, and case management services for its residents. During 2001, the BCCP provided 12,610 mammograms to Maryland women. The proportion of African-American and Hispanic clients that have received services under the BCCP is greater than the proportion of these groups in the Maryland population.

The DHMH formed a Breast Cancer Medical Advisory Committee, which developed guidelines titled “Minimal Clinical Elements for Breast Cancer Screening.” The Minimal Clinical elements provide guidance for public health programs that screen for breast cancer.

Funding from the Cigarette Restitution Fund Program has been awarded to the University of Maryland Medical System/University Care to provide breast and cervical cancer screening for low-income, uninsured or underinsured women who live in Baltimore City. Several other local jurisdictions also offer breast cancer education and screening services under this program. As of January 2004, 1216 women had been screened for breast cancer through these local programs and over 8,608 had received breast and cervical cancer educational services.

Several hospitals offer free breast cancer screening to high risk or symptomatic women who do not qualify for state programs. Funding for these programs is usually from donations and private foundations and tends to vary from one year to the next. Patients needing a work-up or treatment are referred to the Maryland Breast and Cervical Cancer Diagnosis and Treatment Program.

The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program is state-funded and reimburses participating medical providers for breast and cervical cancer diagnostic and treatment services for Maryland residents who are diagnosed with either breast or cervical cancer, meet income guidelines (250% of the poverty level), and are either uninsured or underinsured for these services. This program is not restricted by age.

Figure 10.7
Ideal Breast Cancer Control Model
Step: Prevention

General Public	High Risk Subgroups (e.g., women with suspected inherited cancer syndromes and high-risk benign breast disease)	Primary Care Providers	Medical Specialists
Is aware of general healthy guidelines for breast cancer prevention: diet, physical activity, and weight.	Receives information about her risk of developing breast cancer.	Is aware of and institutes broad prevention interventions (obesity, physical activity, healthy diet).	Provides genetic counseling and testing for individuals regardless of race, ethnicity, and socioeconomic status.
Is aware of her personal risk of breast cancer.	Receives information about genetic counseling and testing if in an appropriate risk group.	Is able to apply and interpret validated risk assessment models (e.g., the Gail model).	Knows risks and benefits of genetic testing, is able to interpret test results, and provides counseling on risk management.
Is aware of age and risk-based recommendations for prevention and early detection of breast cancer.	Receives information about management options to lower the risk of breast cancer (e.g., lifestyle, chemoprevention, and all available proven preventive options).	Is able to identify genetically susceptible high-risk women and refer them for genetic counseling and testing.	Is able to identify women at increased risk who may benefit from chemoprevention, discusses risks and benefits, and provides appropriate follow-up.

**Medical Institutions
(e.g., hospitals)****Research**

Provides access to counseling and management for at-risk populations.

Educes trainees and medical staff in breast cancer risk assessment.

Conducts research to determine what level of risk is most appropriate to define “high-risk”; what percentage of women are “under treated” with respect to prevention; and what percentage are “overtreated” (e.g., inappropriate preventive mastectomies).

Determines the level of knowledge of risk assessment, prevention, and detection guidelines.

Conducts research on best method of risk communication for race/ethnic/socioeconomic subgroups.

Determines the accessibility of risk assessment programs for those at increased risk by race/ethnicity and SES status.

Conducts research on appropriate models for risk counseling and management in order to increase access to care.

Conducts new research on potential prevention interventions associated with low incidence of side effects.

Determines level of knowledge of genetics of cancer and prevention interventions among specialists and primary care providers.

Conducts research to develop culturally appropriate education methods and materials on risk communication.

Assesses institutional support for cancer prevention.

Assesses insurance reimbursement for providers/institutions for preventive services.

Figure 10.8
Ideal Breast Cancer Control Model
Step: Early Detection

Women in Need	Primary Care Providers	Radiologists
Is aware of screening guidelines.	Is aware of current screening guidelines.	Facility is certified by the FDA.
Is provided with culturally diverse materials on early detection.	Discusses screening guidelines with patient (e.g., risks and benefits).	Performs mammogram.
Is aware of, and has access to, screening sites.	Recommends appropriate screening to patient.	Repeats mammogram if results are unsatisfactory.
Is aware of sites offering low- or no-cost screening.	Performs a CBE or refers patient to another provider for a CBE.	Reports results using the Bi-RADS reporting system, including recommendations for follow-up.
Actively seeks out screening.	Refers patient to a surgeon when CBE result is a palpable mass that is of concern to the patient or provider.	Performs or arranges for additional diagnostic procedures (e.g., spot compression, ultrasound, and aspiration).
Receives answers to insurance questions and has barriers to screening reduced.	Refers patient for mammography.	Has dialogue with PCP when results are suspicious.
If in a high-risk subgroup, is aware of, and follows through, with increased monitoring based on own individual profile.	Receives result of mammogram.	Notifies PCP and patient of result of mammogram and other diagnostic tests.
	Refers patient to a surgeon when mammogram result is suspicious or suggestive of malignancy.	
	Reinforces that routine screening is needed.	

The Women's Breast and Cervical Cancer Health Program provides Medicaid coverage to women screened under the BCCP who have been diagnosed with either breast or cervical cancer. Women in this program are eligible for full Medical Assistance while they are undergoing treatment for breast or cervical cancer.

The Maryland State Medical Society provides skills-based clinical breast examination training to primary care providers throughout the state. Physician educators along with patient surrogates train a small group of providers in the MammaCare method. Since 1996, 1,111 Maryland primary care providers have been trained.

The American Cancer Society (ACS) provides advocacy, educational, and support services for breast cancer

patients. Support groups include: I Can Cope, the Cancer Survivor's Network, Reach to Recovery, and Look Good-Feel Better. Assistance with transportation for cancer treatments can be obtained in some areas of the state through the Road to Recovery program. The ACS publishes numerous educational brochures and books, sends speakers to community meetings, and promotes breast cancer screening through its Tell-A-Friend program. ACS also provides free wigs, turbans, prostheses, a cancer information center, a website, and patient navigators for breast cancer patients. The ACS has awarded grants in the amount of \$1,040,200 to two local Maryland institutions for breast cancer research.

The Susan G. Komen Breast Cancer Foundation is a national grant-making and educational foundation dedicated to the eradication of breast cancer as a life-threaten-

Surgeons	Research
Carries out diagnostic procedures (e.g., biopsy).	Researches new techniques for screening and diagnosis.
Uses minimally invasive techniques for diagnosis.	Conducts behavioral research on motivation and acceptance of screening.
Evaluates all palpable, solid, non-cystic masses, regardless of mammographic findings.	Develops culturally appropriate educational materials, including low literacy.
Discusses diagnostic test results with patient and discusses either need for surveillance or treatment options.	Researches barriers to screening.
Performs appropriate TNM staging of the breast cancer.	

Source: Developed by the Breast Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

ing disease by advancing research, education, screening, and treatment. Over the last three years, the Maryland affiliate of the Susan G. Komen Breast Cancer Foundation has awarded grants totaling over \$1.5 million to community groups in the state. These grants support educational outreach programs, foreign language interpreters, the publication of written and video materials, clinical trials nurses, and a limited number of clinical breast examinations and mammograms. In addition to awarding grants, the Maryland affiliate sponsors an annual educational symposium, publishes a resource guide for breast cancer patients, publishes a biannual newsletter, participates in health fairs, makes referrals to various resources, sponsors an annual grant-writing workshop and other educational programs.

Additionally, there are numerous breast cancer support

groups throughout the state.

Numerous laws related to breast cancer have been passed in Maryland. These laws require health insurers and health maintenance organizations to:

- provide coverage for routine mammography screening and prohibit a deductible from being charged for routine mammography screening.
- provide coverage for reconstructive breast surgery following a mastectomy, if the patient requests it. It specifies that coverage is to include surgery on a non-diseased breast to establish symmetry with the diseased breast.
- provide coverage for patient costs incurred as a result of treatment provided in a clinical trial

Figure 10.9
Ideal Breast Cancer Control Model
Step: Treatment

Patients	Treatment Team (surgical, medical and radiation oncologist)
Understands the value of, and has access to, a multi-disciplinary team for treatment.	Is aware of state-of-the-art treatment algorithms for breast cancer treatment (e.g., NCCN).
Has access to culturally appropriate information on breast cancer treatment.	Participates in a multi-disciplinary team for the treatment of breast cancer.
Is aware and informed of the various options for breast cancer treatment.	Discusses the treatment plan with the Treatment Team and provides data for outcomes measurement.
Is provided support by family members, breast cancer support groups, and others.	Discusses options for breast cancer treatment with the patient and provides culturally appropriate written material on breast cancer treatment to the patient.
	Follows state-of-the-art treatment algorithms (NCCN).
	Stage 1 or greater breast cancer evaluated by an oncologist.
	In situ cancer evaluated by an oncologist at the discretion of the surgeon.
	Refers patient to clinical trials, if appropriate.

Figure 10.10
Ideal Breast Cancer Control Model
Step: Long-Term Survivorship

General Public	Patients	Primary Care Providers and Medical Specialists
Understands that one can survive breast cancer.	Asks questions related to survivorship. Is knowledgeable about those issues.	Understands long-term effects of breast cancer treatment (e.g., cardiac, HRT, and recurrence).
Understands the long-term issues affecting breast cancer survivors (e.g., lymphedema, cognitive effects from chemotherapy, radiation and cardiac effects).	Creates a survivorship plan with a lifelong treatment plan outlining who will follow the patient.	Works with the patient and a multi-disciplinary team to create a follow-up and survivorship plan (e.g., which provider is responsible for what kind of follow-up).
Is educated that all women who are getting older are at risk for breast cancer, and thus survivorship.		

**Medical Institutions
(e.g., hospitals)****Research**

Promotes use of multi-disciplinary teams for breast cancer treatment.

Is committed to a high-functioning cancer tumor committee within the institution.

Establishes and provides fellowship programs in breast disease.

Advocates and applies for competitive research grants, particularly those that place emphasis on community hospitals and access to clinical trials.

Is culturally appropriate in its approach to patients.

Evaluates the utilization of new treatment procedures in the Maryland Cancer Registry (e.g., sentinel lymph node biopsy).

Researches factors contributing to late stage breast cancers in Maryland.

Source: Developed by the Breast Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

**Medical Institutions
(e.g., hospitals)****Research**

Offers programs like a navigator and buddy/match program, support groups, (e.g., Reach to Recovery.)

Offers one place to call for survivorship referral.

Conducts research on the long-term effects of adjuvant therapy on survivorship (e.g., lymphedema, cognitive effects from chemotherapy, and radiation and cardiac effects).

Conducts research on how to alleviate the fear of recurrence.

Conducts research on how to prevent recurrence.

Conducts research on issues faced by young survivors.

Source: Developed by the Breast Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

for: (1) a life-threatening condition or (2) prevention, early detection, and treatment studies on cancer. In conjunction with the above-mentioned coverage, a carrier must provide coverage for costs incurred by patients for FDA-approved drugs and devices, whether or not the FDA has approved the drug or device for treating the enrollee's particular condition.

- pay for a minimum of 48 hours of inpatient care following a mastectomy. For patients having outpatient surgery or who remain in the hospital less than 48 hours insurance companies must pay for a minimum of one home visit within 24 hours following discharge.
- provide coverage for a breast prosthesis that has been prescribed by a physician for an enrollee or insured who has undergone a mastectomy and has not had breast reconstruction.
- reimburse patients (up to \$350) for the cost of a hair prosthesis when the loss of hair is due to chemotherapy or radiation treatments for cancer.

These laws are for physicians:

- Physicians who treat breast cancer patients are required to provide them with a written summary (to be provided by DHMH) describing various breast cancer treatments.
- Physicians who perform breast implantations are required to provide patients with a standardized written summary (provided by DHMH) describing the advantages, disadvantages, and risks associated with breast implantation.

Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁷³ related to breast cancer:

Objective:

Reduce the female breast cancer death rate to 22.3 per 100,000.

The U.S. baseline was 27.9 per 100,000 in 1998 (age-adjusted to the 2000 U.S. standard population).

Objective:

Increase the proportion of women aged 40 years and older who have received a mammogram within the preceding 2 years to 70%.

The U.S. baseline was 67% of women aged 40 years and older received a mammogram within the preceding 2 years in 1998 (age-adjusted to the 2000 U.S. standard population).



Breast Cancer Goals, Objectives, and Strategies

Goals:

1. Reduce the incidence of breast cancer in Maryland.
2. By 2008, reduce the proportion of late stage breast cancers diagnosed in all women and reduce the rates of late diagnosis in African-American women to that of white women.
3. Ensure that all women who develop breast cancer are diagnosed with Stage 1 disease with <1 cm tumors.
4. Research factors contributing to high incidence and mortality rates in Maryland and develop appropriate interventions (e.g., conduct a case-control study to compare Maryland's Delmarva region to low mortality regions in the United States and examine for possible explanatory factors).
5. Ensure access to prevention, screening, treatment, and follow-up care for all Maryland residents.
6. Preserve the Cigarette Restitution Fund (CRF) for addressing health issues in Maryland.

Targets for Change

By 2008, reduce the female breast cancer mortality to a rate of no more than 23.2 per 100,000 females in Maryland.

The Maryland baseline was 27.7 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Department of Health Statistics.

By 2008, increase the number of women age 40 and older that received a mammogram in the past two years to 85%.

The Maryland baseline was 82% in 2000.

Source: BRFSS.

Objective 1:

Determine why Maryland has high breast cancer incidence and mortality rates compared to other states in the nation.

Strategies:

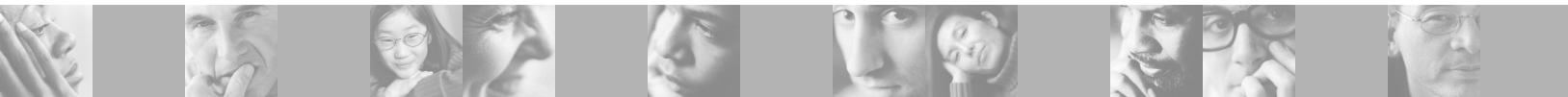
1. Conduct research to determine what factors are associated with increased incidence, late stage diagnosis, and mortality in Maryland.
2. Intervene on those factors associated with high incidence, high mortality, and late stage breast cancer that can be modified.
3. Maintain and expand the Maryland Cancer Registry in order to identify problems, conduct research, and evaluate the effectiveness of interventions.
4. Explore the possibility of providing open access to the CRF for research and interventions to all health related organizations in the state.

Objective 2:

Continue to monitor breast cancer prevention research and promote activities to prevent breast cancer.

Strategies:

1. Assess existing interventions and conduct multi-faceted interventions to reduce obesity and increase physical activity, known factors associated with the risk of breast cancer. Interventions should cover all age groups, including children as well as adults.
2. Create a primary prevention committee within the State Council on Cancer Control to ensure that cancer prevention issues receive appropriate attention.
3. Develop and conduct interventions to promote other factors associated with a lower risk of developing breast cancer, such as breast-feeding.



4. Provide risk-based literature that is culturally and ethnically appropriate.
5. Provide access to breast cancer prevention trials to all Maryland residents.

Objective 3:

Increase breast cancer risk assessment and risk-appropriate strategies.

Strategies:

1. Conduct research to determine what individuals and providers know about breast cancer risk assessment and management and their current practices related to risk assessment and management.
2. Educate providers and women about assessing breast cancer risk and risk-appropriate management options.
3. Determine mechanisms to promote the practice of breast cancer risk assessment.
4. Conduct research to determine the prevalence of high-risk groups.
5. Evaluate and ensure access to counseling and care for high-risk groups (regardless of race, ethnicity, SES, etc.), including genetic counseling and testing, counseling regarding chemoprevention and access to medications, and other risk management options such as prophylactic surgery.
6. Provide culturally appropriate risk assessment materials to providers for their practices.
7. Create centers throughout the state so that all residents have access to information on breast cancer risk, prevention interventions, and specialized services for high-risk groups (regardless of race, ethnicity, SES, etc.).

Objective 4:

Ensure continued access to early detection and treatment of breast cancer.

Strategies:

1. Continue federal and state funding for the breast cancer early detection and treatment program.
2. Develop culturally appropriate education and outreach activities appropriate to the various and diverse population groups in the state.
3. Provide all residents with access to breast cancer treatment trials.

Objective 5:

Increase the number of providers that perform minimally invasive biopsy techniques.

Strategies:

1. Evaluate patterns of care across regions and racial groups.
2. Educate providers and patients regarding minimally invasive biopsy techniques.
3. Facilitate utilization of minimally invasive techniques.

**Objective 6:**

Promote optimum state-of-the art breast cancer care for all breast cancer patients regardless of regional, racial, age, or other disparities.

Strategies:

1. Utilize the Maryland Cancer Registry Data to evaluate patterns of care by region, race, and age and to provide performance evaluation to providers.
2. Educate providers to improve their patients' access to care.
3. Educate the public and providers on standards of care.
4. Develop culturally sensitive materials about breast cancer treatment options.
5. Encourage insurance companies to compensate providers for case management services.

Objective 7:

Increase the number of individuals with Ductal Carcinoma in Situ (DCIS) and early stage breast cancer that receive treatment appropriate for their diagnosis.

Strategies:

1. Implement state-of-the-art treatment for women with DCIS and early stage breast cancer in order to avoid both over-treatment and under-treatment of breast cancer.
2. Promote research to more accurately identify patients with early stage disease that will most likely progress, in order to better tailor therapy.
3. Determine if risks/benefits, including long-term risks, of therapy are adequately discussed with patients.
4. Develop risk/benefit fact sheets for patients with DCIS and early stage breast cancer.

Objective 8:

Provide breast cancer survivors with information regarding the long-term effects of treatment.

Strategies:

1. Conduct research to determine the long-term effects of treatment.
2. Conduct research to determine providers' knowledge of long-term treatment effects and practices regarding discussion of effects with patients.
3. Develop "standards of care" for long-term survivors and educate patients and providers regarding these standards.
4. Educate patients and providers about long-term effects of breast cancer treatment.
5. Develop and evaluate models for long-term care incorporating prevention of new cancers, recurrence of breast cancer, prevention and screening for other cancers, and potential long-term effects of treatment.

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CHAPTER 11

PROSTATE CANCER

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PROSTATE CANCER

The prostate is a small gland that is located beneath the bladder and in front of the rectum in men. It is part of the male reproductive system and produces a fluid that is part of semen. The prostate gland surrounds the tube that empties urine from the bladder and tends to grow with age. If the prostate gland grows too large, the flow of urine from the bladder can be slowed or stopped.¹

Prostate cancer is the growth of cancerous cells in the prostate and it is the most common cancer among men. By age 75, approximately 50%–75% of men will have prostate cancer. Most prostate cancers develop in older men, and, compared with most cancers, tend to grow slowly. Some prostate cancers are slow-growing (indolent), do not produce symptoms, and may never be life threatening, while other prostate

cancers may progress and spread rapidly. When symptoms do appear, they are similar to those caused by benign prostatic hyperplasia (BPH or enlargement of the prostate). Although prostate cancer is a major cause of cancer deaths, many more men are diagnosed with this cancer than die from it. Men in the U.S. have a 15% lifetime risk of being diagnosed with prostate cancer but only a 3% lifetime risk of dying from the disease.^{2,3,4}

Risk Factors

The causes of prostate cancer are not known. Certain risk factors may increase the chance of developing prostate cancer, including the following:

Age

Older age is the most important risk factor for developing prostate cancer. Prostate cancer rates increase with increasing age. More than 75% of prostate cancers are diagnosed in men aged 65 and older; just 7% of cases occur in men younger than age 60.^{5,6}

Family history

Men with a first-degree relative (e.g., father or brother) who has developed prostate cancer are more than twice as likely to develop prostate cancer as men without a family history.⁷

Table 11.1
Prostate Cancer Incidence and Mortality By Race,
Maryland and the United States, 1999

Incidence 1999	Total	Whites	Blacks
New Cases (#)	3,869	2,556	904
Incidence Rate*	185.3	157.4	226.8
U.S. SEER Rate*	174.8	167.8	265.6
Mortality 1999	Total	Whites	Blacks
MD Deaths (#)	574	380	188
MD Mortality Rate*	34.1	28.1	67.4
U.S. Mortality Rate*	31.1	28.6	67.8

*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

Race

The risk of developing prostate cancer is significantly higher among blacks than whites.⁸

Studies suggest possible links with the following risk factors:

Dietary fat

A diet high in fat may be associated with an increased risk of prostate cancer.⁹

Dietary fruits and vegetables

Increased dietary intake of fruits and vegetables may be protective and has been associated with a reduced risk of prostate cancer in some studies.¹⁰

Burden of Prostate Cancer in Maryland

Prostate cancer is the most commonly diagnosed cancer among men in Maryland and the United States. In 1999 a total of 3,869 cases of prostate cancer were diagnosed in Maryland. The age-adjusted prostate cancer incidence rate in Maryland in 1999 is 185.9 per 100,000 men; this rate is significantly higher than the 1999 U.S. SEER age-adjusted prostate cancer incidence rate of 174.8 per 100,000 men (Table 11.1).

Prostate cancer incidence is highest among blacks. In Maryland the prostate cancer incidence rate for black males is 226.8 per 100,000 compared to a rate of 157.4 per 100,000 for white males.¹¹ Prostate cancer incidence is 40% higher in black men compared to white men,

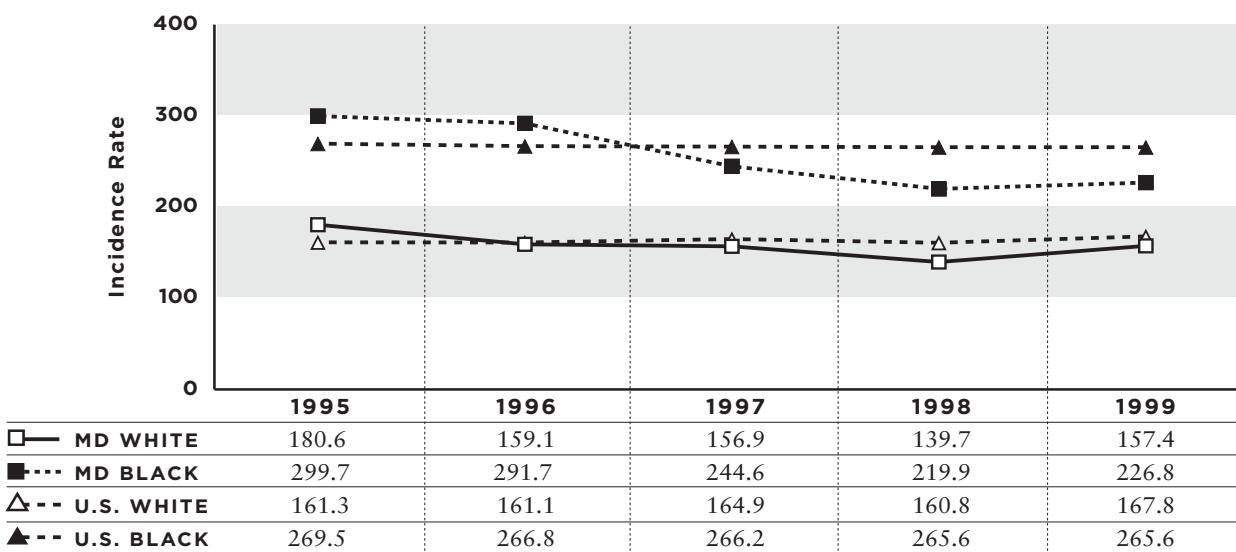
while rates for Hispanic and Asian American men are lower than those for white men. The lowest prostate cancer incidence rates are found in Native Americans.¹²

Prostate cancer incidence rates in the U.S. increased modestly between 1973 and 1986. With the advent of prostate specific antigen (PSA) testing in 1986, prostate cancer incidence rates increased dramatically from 1986 to 1993. Since 1993, prostate cancer incidence rates have been decreasing towards the rates just prior to the adoption of PSA testing.¹³ Prostate cancer incidence rates in Maryland have decreased an average of 1.4% per year from 1995 to 1999 (Figure 11.1). It is thought that this decline may be an artifact of PSA testing.

The incidence of prostate cancer increases with age and peaks between ages 70 and 74 (Figure 11.2). Incidence rates for men 50–54 years of age are 116.4 per 100,000 for whites and 209.8 per 100,000 for blacks, while rates for men 70–74 years of age are 995.5 per 100,000 for whites and 1,609.3 per 100,000 for blacks in Maryland.¹⁴

Prostate cancer incidence rates vary by geographic region in Maryland. Prostate cancer incidence rates in 1999 were highest in Charles County (237.4), Baltimore City (216.8), Dorchester County (216.8), Carroll County (210.6), Cecil County (207.6), Harford County (202.9), and Prince George's County (199.0).

Stage of disease refers to the progression of cancer at the time of diagnosis. Local stage means that the prostate cancer is confined to the prostate gland. Regional stage means that the prostate cancer has grown beyond the

Figure 11.1**Prostate Cancer Incidence Rates by Race in Maryland and the United States, 1995–1999**

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995–1999; SEER, National Cancer Institute, 1995–1999.

prostate gland to surrounding organs or tissues and/or regional lymph nodes. Distant stage means that the prostate cancer has spread to other parts of the body remote from the primary tumor, such as the bone.

From 1992 to 1998, 85% of prostate cancers in white men and 80% in black men in the United States were detected at the local or regional stage, while 6% of prostate cancers in white men were diagnosed at the distant stage compared to 9% in black men.¹⁵ Hawaiians, American Indians, and blacks have the highest proportion of men diagnosed with distant stage disease.¹⁶ A large proportion (31.5%) of prostate cancers in Maryland are unstaged (i.e. the stage of disease was not reported or staging tests were not needed or not performed). Because the stage distribution of these unstaged prostate cancers is not known, interpretation of overall prostate cancer stage distribution in Maryland is difficult.

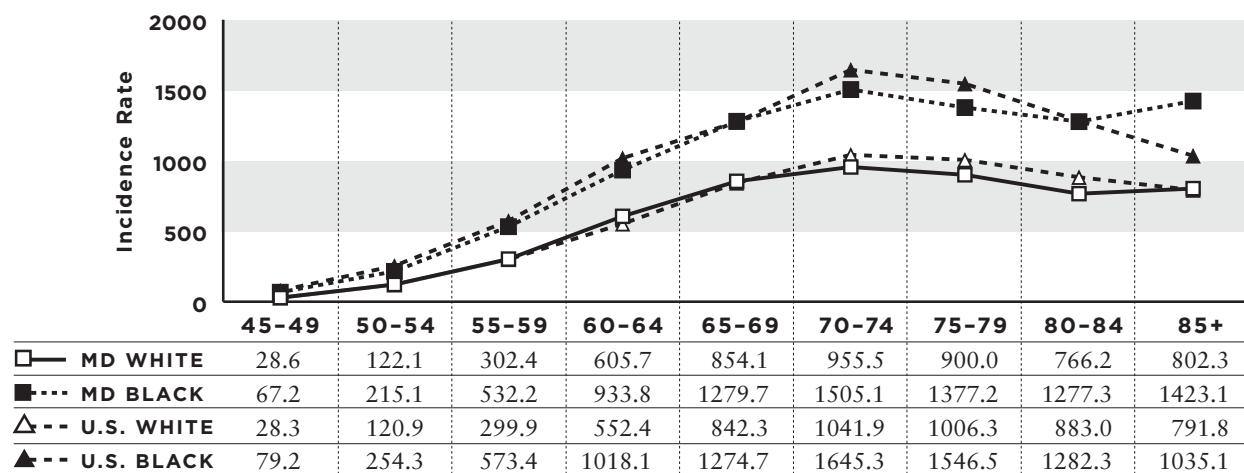
There have been significant improvements in the five-year relative survival rates for prostate cancer between 1973 and 1995, with overall five-year survival rates increasing from 64% in 1973 to 92.9% in 1995. Five-year relative survival rates for local and regional stage in 1995 is almost 100%, while five-year survival rates for distant disease is only 34%. Five-year relative survival rates for distant stage prostate cancer have not improved over time.¹⁷

Although overall survival rates have increased over time for both white and black men, five-year relative survival rates for black men are lower than that for white men (92% versus 97%).¹⁸ Five-year relative survival rates are lower among younger men compared to older men (84.1% for men aged 40–49 years versus 96.8% for men aged 70–75 years). For local and regional stage prostate cancers, American Indians have the lowest survival rates. For distant stage prostate cancers, blacks, Hispanics, and American Indians have the lowest survival rates.¹⁹

Prostate cancer is the second leading cause of cancer death among men in Maryland and the United States. In 1999, 574 Maryland men died of prostate cancer. The age-adjusted prostate cancer mortality rate in Maryland in 1999 was 34.1 per 100,000 men. This rate is statistically significantly higher than the 1999 U.S. age-adjusted prostate cancer mortality rate of 31.1 per 100,000 men.²⁰ Maryland had the tenth highest prostate cancer mortality rate in the country for the time period 1995–1999.

Prostate cancer mortality is over twice as high among blacks than whites in both Maryland and the U.S., and is lowest among American Indians. Prostate cancer mortality rates are lower among Hispanics than non-Hispanics.²¹ The age-adjusted prostate cancer mortality rate for black men in Maryland in 1999 was 67.4 per 100,000 compared to a rate of 28.1 per 100,000 for white men in Maryland (Table 11.1).

Figure 11.2
Prostate Cancer Age-Specific Incidence by Race in Maryland and the United States, 1995-1999



Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Prostate cancer mortality rates have been decreasing since 1990, declining an average of 5.1% per year from 1995 to 1999 in Maryland²² (Figure 11.3). Prostate cancer mortality increases with age. Approximately 90% of prostate cancer deaths occur among men older than 65 years of age.²³

Prostate cancer mortality varies by geographic region in Maryland. As shown in Figure 11.4, prostate cancer mortality rates from 1995–1999 were statistically significantly higher than the U.S. in Baltimore City and Prince George's County.²⁴

Disparities

- Prostate cancer incidence is over 44% higher among black men than white men.
- Prostate cancer mortality is over twice as high among black than white men.

Primary Prevention

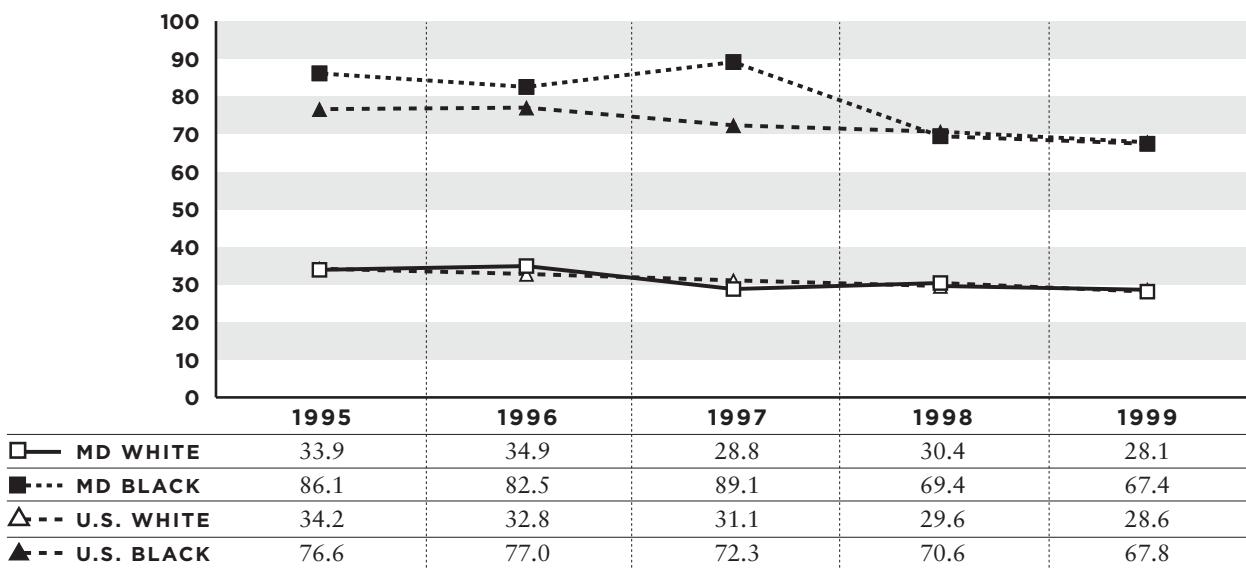
Although the cause of prostate cancer is not known, research is underway to discover what individuals can do to reduce their risk of developing the disease. This research includes epidemiologic studies (i.e. population-based research) on diet and other lifestyle factors

and chemoprevention trials.²⁵ Although approaches to primary prevention of prostate cancer are being tested, to date, none are known to be effective.²⁶

Chemoprevention is the use of drugs, natural or man-made vitamins, or other agents to reverse, suppress, or prevent the growth of cancer. Several agents including finasteride, dutasteride, difluoromethylornithine (DFMO), isoflavonoids, selenium, vitamins D and E, and lycopene have shown potential benefit in preclinical or early clinical studies. Further studies are needed to confirm this.²⁷ The Prostate Cancer Prevention Trial (PCPT), testing whether finasteride (a drug that lowers the hormone dihydrotestosterone), reduces the prevalence of prostate cancer, is nearly completed. The REDUCE trial, a test of dutasteride (a drug related to finasteride) for prostate cancer prevention, has just started. The SELECT trial, studying whether selenium and vitamin E can reduce the incidence of prostate cancer, is currently being conducted.²⁸

Screening

The two principal methods of screening for prostate cancer are the digital rectal examination (DRE) and the prostate specific antigen blood test (PSA). The DRE is a physical exam in which the physician inserts a gloved and lubricated finger into the rectum to feel the back

Figure 11.3**Prostate Cancer Mortality Rates by Race in Maryland and the United States, 1995-1999**

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995-1999; SEER, National Cancer Institute, 1995-1999.

portion of the prostate gland. Prostate specific antigen is a protein that is produced by the prostate, circulates in the blood, and can be detected and measured with a blood test. This is the PSA test. PSA levels may be elevated in men who have prostate cancer, BPH, or prostatitis (inflammation of the prostate).²⁹ Approximately half of men who have BPH have elevated levels of PSA.³⁰

PSA testing in combination with DRE has increasingly become part of routine preventive care. Data from the Maryland Behavioral Risk Factor Surveillance System in 1999 and 2001 show that 76% of Maryland men report that they have “ever” had a PSA test, and 59% report that they have had a PSA test in the past year. The percentage of men who reported “ever” having a PSA test increased from 50% in 1994 to 75% in 1999. The percentage of men who reported having a PSA test in the past year increased from 42% in 1994 to 58% in 1999. Men with a high school education or less report the lowest levels of PSA testing, while men with a college education or higher reported the highest levels of PSA testing. Men with incomes less than \$15,000 a year are significantly less likely to get PSA testing than men with incomes over \$75,000 per year. There are no significant differences in PSA screening rates by race or jurisdiction in Maryland.³¹

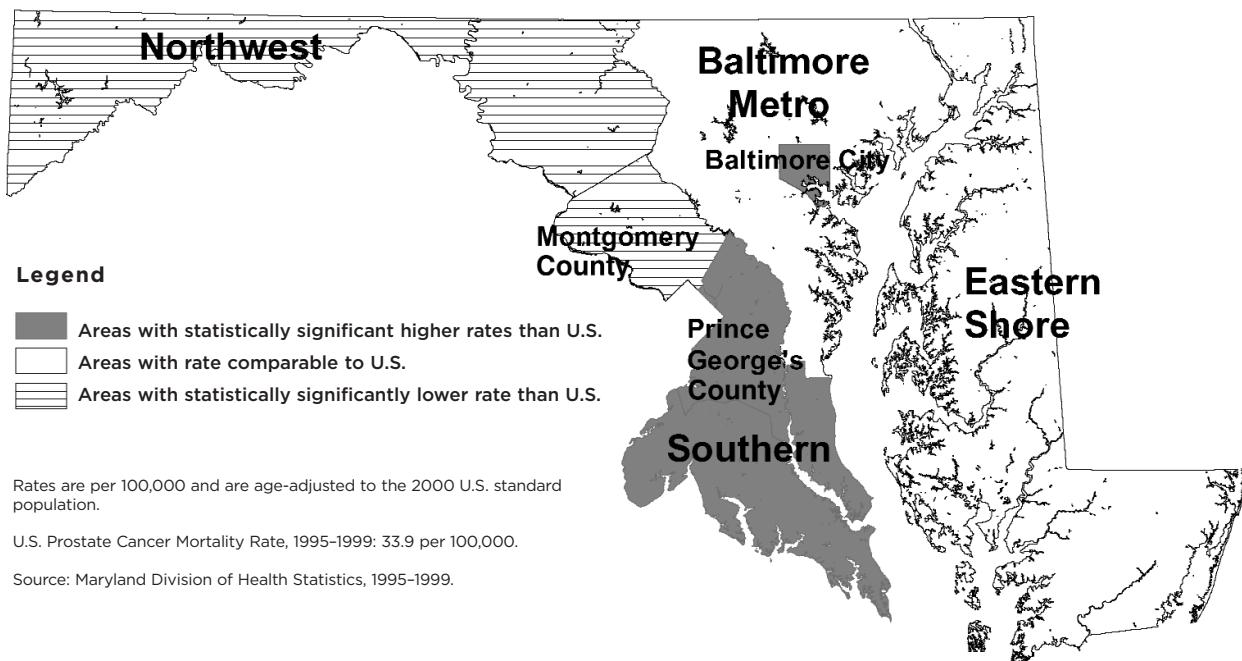
PSA levels are also used to monitor men who have undergone treatment for prostate cancer with surgery (radical prostatectomy) or radiation therapy to determine if the prostate cancer recurs. In addition, PSA levels are also monitored in men with elevated PSA levels who choose watchful waiting; this is done in order to determine if there is a change in PSA levels that may warrant treatment.

Effectiveness of Early Detection and Treatment

The first randomized controlled trial of prostate cancer screening using PSA and DRE (i.e. the 1988 Quebec prospective randomized control trial), which reported a benefit from screening, was hampered by a low rate of screening in the intervention group (23%) and by flaws in the published analysis. No difference in the number of prostate cancer deaths was observed between the group randomized to screening versus the group receiving usual care. Three well-conducted case-control studies of DRE showed mixed results. Two other randomized controlled trials of prostate cancer screening, both initiated in 1994, are ongoing: the National Cancer Institute’s Prostate, Lung, Colorectal and Ovarian Trial (PLCO) and the European Randomized Study on Screening for

Figure 11.4

**Maryland Prostate Cancer Mortality Rates by Geographical Area:
A Comparison to Rates in the United States, 1995-1999**



Prostate Cancer (ERSPC). Neither of these studies will have data on mortality for several years. Currently it is not known if prostate cancer screening reduces prostate cancer mortality.³²

In its December 2002 update, the U.S. Preventive Services Task Force (USPSTF) concluded that “the evidence is insufficient to recommend for or against routine screening for prostate cancer using PSA testing or digital rectal examination.” The USPSTF found good evidence that PSA and DRE screening can detect prostate cancer in its early stages, but found mixed and inconclusive evidence that such early detection reduces prostate cancer deaths or improves health outcomes. Although early detection and treatment might prevent some cancers from spreading, it is also likely to detect other cancers that would have grown slowly and not caused health problems. Screening is associated with potential harms including false positive results, unnecessary biopsies, and complications from treatment (e.g., urinary incontinence, erectile dysfunction, and bowel dysfunction) of some cancers that may never have affected a patient’s health. If early detection improves health outcomes, the population most likely to benefit from screening would be men aged 50 to 70 who are average risk, and men older than 45 who are at increased risk (i.e. African-American men and men with a first degree relative with

prostate cancer). Benefits may be smaller in Asian Americans, Hispanics, and other racial and ethnic groups that have a lower risk of prostate cancer. Older men and men with other significant medical problems who have a life expectancy of less than 10 years are unlikely to benefit from screening.³³

Data are also limited to determine whether treatment of screening-detected cancers improves outcomes. A recent randomized controlled trial reported that radical prostatectomy, compared with watchful waiting, significantly reduced prostate cancer mortality and the risk of distant metastasis in men whose cancer was detected clinically after they reported symptoms.³⁴ Whether these findings apply equally to prostate cancers found during routine screening in the absence of symptoms is not yet certain. Ongoing screening trials and trials of treatment versus watchful waiting for cancers detected by screening may help to clarify the benefits of early detection of prostate cancer.³⁵

Screening Recommendations of Professional Groups

Conflicting recommendations on prostate cancer screening have been issued by various professional groups and

are summarized in Table 11.2. The American Cancer Society and the American Urological Association recommend that health professionals offer testing for the early detection of prostate cancer. Other organizations do not advocate for routine testing for prostate cancer.

The one area that these professional organizations agree on is helping patients make informed decisions regarding prostate cancer screening. Most major U.S. medical organizations recommend that clinicians discuss with patients the potential benefits and uncertainties regarding prostate cancer detection and subsequent treatment, consider individual patient preferences, and individualize the decision to screen. There is general agreement that the most appropriate candidates for screening include men 50 years of age and older who are at average risk and younger men who are at increased risk of prostate cancer, but screening is unlikely to benefit men who have a life expectancy of less than 10 years. These organizations include the American Cancer Society, American College of Physicians, American Society of Internal Medicine, American College of Preventive Medicine, American Academy of Family Physicians, American Medical Association, American Urological Association, and National Comprehensive Cancer Network.

Treatment

Treatment for prostate cancer may involve surgery, radiation therapy, or hormonal therapy. Some patients receive a combination of therapies; other patients choose to be monitored (watchful waiting) instead and are treated if their PSA levels rise. Treatment options vary based on the stage of the disease at the time of diagnosis. Options for early stage prostate cancer include watchful waiting, treatment with surgery, or radiation therapy. Watchful waiting may be suggested for some men whose prostate cancer appears to be slow growing, for older men, or men with serious medical problems. For these men, the risks and possible side effects of surgery or radiation therapy may outweigh the possible benefits. Surgery may involve removal of all or part of the prostate gland. Radiation therapy may involve external beam radiation or the insertion of radioactive seeds placed inside or near the tumor (brachytherapy). Hormonal therapy combats prostate cancer by cutting off the supply of male hormones that encourage prostate cancer growth. Hormonal control can be achieved by drugs or by surgery to remove the testicles.⁴⁴ In addition, clinical trials are being conducted to determine new ways of treating prostate cancer.

The efficacy of various types of treatment for localized prostate cancer, especially the type of localized prostate cancer detected by screening, is largely unknown. While one randomized controlled trial showed that radical prostatectomy reduced prostate cancer mortality compared to watchful waiting in men with symptomatic localized disease, the benefit to persons screened is still unknown. There is no direct evidence that radiation therapy or androgen deprivation therapy is effective for clinically localized cancer.⁴⁵

Each treatment for prostate cancer is associated with various potential complications or harms, including erectile dysfunction, urinary incontinence, and bowel problems (e.g., diarrhea, rectal bleeding). The magnitude of the potential complications from treatment is summarized in Table 11.3.

Informed Decision-Making

The uncertainties of the benefits of screening versus the potential complications of treatment for prostate cancer has led many organizations to recommend that men be informed about the benefits and risks of PSA screening and give consent for PSA screening.⁴⁶ The Prostate Cancer Medical Advisory Committee of the Maryland Department of Health and Mental Hygiene reviewed recent literature on informed decisionmaking for prostate cancer screening, discussed the information that men should be given prior to screening, and provided information that should be discussed with men prior to screening in its “Prostate Cancer Minimal Elements for Information, Screening, Diagnosis, Treatment and Follow-up.”⁴⁷ The information recommended by the Prostate Cancer Medical Advisory Committee for informed decisionmaking regarding prostate cancer screening is summarized in Table 11.4.

According to a recent study, there are differences in the ways African Americans, Hispanics, and Caucasians want information about prostate cancer screening. African Americans wanted information about how they are at higher risk for prostate cancer and have higher mortality rates compared to Caucasians. African Americans and Caucasians wanted information on the advantages and disadvantages of PSA and DRE, whereas Hispanics wanted general information about PSA testing. Caucasians placed emphasis on the fact that early prostate cancer can be asymptomatic. According to this study, Caucasians and African Americans sought a more active role in informed decisionmaking than Hispanics. This one study shows how

Table 11.2
Prostate Cancer Screening Recommendations of Professional Organizations^{36, 37, 38, 39, 40, 41, 42, 43}

Professional Organization	Informed Decision-Making to Screen?	Patient Screening Recommendations	Date Guideline Developed
American Cancer Society	Yes	<p>Information should be provided to men regarding the potential risks and benefits of early detection of prostate cancer.</p> <p>PSA and DRE should be offered annually beginning at age 50 for men who have at least a 10-year life expectancy. High-risk men (African Americans, men with one or more first-degree relatives diagnosed at a young age) should begin testing at age 45.</p>	1/2003
American College of Physicians/ American Society of Internal Medicine	Yes	<p>Physicians should enroll eligible men in ongoing clinical studies.</p> <p>Rather than screen men for prostate cancer as a matter of routine, physicians should describe the potential benefits and known harms of screening, diagnosis, and treatment; listen to patient's concerns; and then individualize the decision to screen.</p>	3/1997
American College of Preventive Medicine	Yes	<p>Recommends against routine population screening with DRE and PSA.</p> <p>Men age 50 and older with a life expectancy of more than 10 years should be given information about the potential benefits/harms of screening and the limits of current evidence and should be allowed to make their own choice about screening, in consultation with their physician, based on personal preference.</p>	7/1998
American Academy of Family Physicians	Yes	Men aged 50-65 years of age should be counseled regarding the known risks and uncertain benefits of screening for prostate cancer.	9/2002

Continued

Table 11.2 (Cont.)**Prostate Cancer Screening Recommendations of Professional Organizations**^{36, 37, 38, 39, 40, 41, 42, 43}

Professional Organization	Informed Decision-Making to Screen?	Patient Screening Recommendations	Date Guideline Developed
American Medical Association	Yes	<p>Launching of mass screening programs for the early detection of prostate cancer is premature at this time.</p> <p>All men who would be candidates for and who are interested in active treatment for prostate cancer should be provided with information regarding their risk of prostate cancer and the potential benefits and harms of prostate screening to support well-informed decision making.</p> <p>Prostate cancer screening, if elected by the informed patient, should include PSA testing and DRE. Men most likely to benefit from screening should have a life expectancy of at least 10 years and include African-American men 40 years or older, men 40 years of age or older with an affected first degree relative, and men 50 years of age or older.</p>	N/A
American Urological Association	Yes	<p>The decision to use PSA for the early detection of prostate cancer should be individualized. Patients should be informed of the known risks and the potential benefits.</p> <p>Early detection of prostate cancer should be offered to asymptomatic men 50 years of age or older with an estimated life expectancy of more than 10 years. It is reasonable to offer testing at an earlier age to men with defined risk factors, including men with a first-degree relative who has prostate cancer and African-American men.</p>	2/2000
National Comprehensive Cancer Network	Yes	<p>The decision to take part in an early detection program for prostate cancer is complex for both patient and physician. Important factors that must be considered when beginning an early detection program include patient age, life expectancy, family history, race, prior early detection tests, and most importantly, an understanding of the risks and benefits associated with the early detection and treatment of prostate cancer.</p>	10/2002

Continued

Table 11.2 (Cont.)

Professional Organization	Informed Decision-Making to Screen?	Patient Screening Recommendations	Date Guideline Developed
National Comprehensive Cancer Network	Yes	<p>Screening candidates:</p> <p>Normal risk: men aged 50 or older with a life expectancy of more than 10 years. Risk/benefit discussion should begin at age 50.</p> <p>High risk: African-American men, men with a family history of 2 or more affected first-degree relatives and a life expectancy of more than 10 years. Risk/benefit discussion should begin at age 45.</p>	10/2002
U.S. Preventive Services Task Force	Yes	Evidence is insufficient to recommend for or against routine screening for prostate cancer using PSA and DRE.	12/2002

Table 11.3
Potential Magnitude of Harms Resulting from Prostate Cancer Treatments*

Treatment	% of Patients with Reduced Sexual Function	% of Patients with Urinary Problems	% of Patients with Bowel Problems	% of Patients with Other Problems
Radical prostatectomy	20%–70%	15%–50%	-	-
External beam radiation therapy	20%–45%	2%–16%	6%–25%	-
Brachytherapy	36%+	6%–12%	18%	-
Androgen deprivation therapy	40%–70%	-	-	Breast swelling: 5%–25% Hot flashes 50%–60%

*Percent of patients treated who had side effects at least 12 months after treatment.

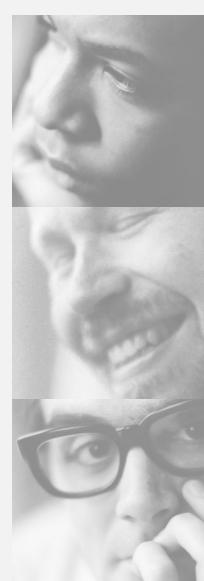
+These findings are less certain than the other entries because they are based on less, or less good, evidence.

Source: U.S. Preventive Services Task Force. Guide to Clinical Preventive Services. Screening for Prostate Cancer. Ann Intern Med 2002 Dec 3;137(11):915-16.

Table 11.4
Facts for Informed Decision-Making
for Prostate Cancer Screening

- Prostate cancer is the most common cancer among men and is the second leading cause of cancer deaths in men.
- Certain men are at higher risk of prostate cancer; African-American men, men with a father, brother, or son with prostate cancer, and men over 50 are at higher risk.
- Those who will benefit most from prostate cancer screening are men who are 50 to 70 years of age and men who are 45 to 70 years of age who are African-American, or who have a father, brother, or son with prostate cancer.
- The digital rectal exam is an exam in which the doctor examines the prostate gland by putting a finger inside the rectum.
- The PSA (prostate specific antigen) test is a blood test for prostate cancer.
- The PSA and DRE are both used to screen for prostate cancer.
- The PSA test can find prostate cancer earlier than the DRE alone.
- The PSA test can be high because of other prostate problems, so it does not always indicate cancer. Also, the PSA test can sometimes be normal even if a man has prostate cancer.
- A PSA test that is high may lead to a biopsy of the prostate gland to see whether a man has prostate cancer; and a biopsy may have complications.
- No one is sure yet whether DRE and PSA tests will reduce the number of deaths from prostate cancer. Some information suggests that screening may lower the number of deaths.
- A man who has early prostate cancer can choose how to handle his cancer: he and his doctor may choose to wait and watch to see if the prostate cancer is changing, or he may choose to be treated with surgery, radiation therapy, or hormonal therapy.
- If a man chooses to have treatment, there are often side effects of treatment.
- If a man has a PSA and a DRE, he will get the results of his tests and have a chance to talk to someone knowledgeable about what the results mean and what his options are.

Source: Maryland Department of Health and Mental Hygiene, Prostate Cancer Medical Advisory Committee, Minimal Elements for Information, Screening, Diagnosis, Treatment and Follow-up, July 2002.



important it is that physicians promoting informed decisionmaking about controversial screening tests take cultural sensitivity into account when designing and using educational interventions.⁴⁸

Current Efforts

Prostate cancer screening is commonly offered to patients in physicians' offices. In addition, several community hospitals and organizations offer prostate cancer screening in their communities on special occasions. The Prostate Cancer Medical Advisory Committee of the Maryland State Department of Health and Mental Hygiene has developed guidelines entitled "Prostate Cancer Minimal Elements for Information, Screening, Diagnosis, Treatment and Follow-up" to provide guidance for public health programs that decide to screen for prostate cancer.⁴⁹

Under the Maryland Cigarette Restitution Fund Program, the Johns Hopkins Medical Institutions are implementing a public health prostate cancer early detection program in Baltimore City. Several other local jurisdictions offer prostate cancer education and screening services under this program. As of January 2004, 1,082 men had been screened through these local programs, and over 20,000 had received educational services. The month of September has been designated as prostate cancer awareness month.

Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁵⁰ related to prostate cancer:

Objective:

Reduce the prostate cancer death rate to 28.8 per 100,000 population.

The U.S. baseline was 32.0 per 100,000 in 1998 (age-adjusted to the 2000 U.S. standard population).

(There are no Healthy People 2010 objectives for prostate cancer screening.)



Prostate Cancer Goals, Objectives, and Strategies

Goals:

Reduce prostate cancer mortality.

Reduce disparities in the mortality of prostate cancer.

Monitor the proportion of men who have had a PSA test and a digital rectal examination.

Target for Change

By 2008, reduce prostate cancer mortality to a rate of no more than 25.8 per 100,000 persons in Maryland.

The Maryland baseline was 31.9 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Division of Health Statistics.

Objective 1:

Increase public education about prostate cancer.

Strategies

1. Formulate educational messages about prostate cancer.
2. Educate African-American men and men with a family history of prostate cancer in a first degree relative about prostate cancer and what is known about prostate cancer prevention and early detection.
3. Assure that educational materials take into account cultural differences when developing and implementing educational interventions.

Objective 2:

Continue to monitor research findings regarding the effectiveness of primary and secondary prevention interventions in reducing prostate cancer mortality.

Strategies:

1. Interpret and translate research findings regarding primary and secondary prevention to the public.
2. Promote a healthy diet and active lifestyle as a general guide to good health.

Objective 3:

Promote informed decisionmaking prior to screening with PSA and digital rectal examination.

Strategies:

1. Disseminate the "Minimal Elements for Prostate Cancer Education, Screening, Diagnosis, Treatment and Follow-up" developed by the Prostate Cancer Medical Advisory Committee of DHMH to health care providers who screen men for prostate cancer.
2. Convey the benefits and risks of screening to health professionals, community leaders, the general public, and men to be screened.



3. Encourage documentation of informed consent prior to prostate cancer screening.
4. Develop questions regarding informed decision-making for prostate cancer screening to add to the Maryland Cancer Survey in order to measure the extent to which providers are discussing the benefits and risks of prostate cancer screening with men.
5. Promote the use of the “Minimal Elements for Information, Screening, Diagnosis, Treatment and Follow-up” guidelines for all prostate cancer screenings that take place outside of a physician’s office.

Objective 4:

Promote education about prostate cancer treatment and support services for patients diagnosed with prostate cancer.

Strategies:

1. Educate patients about prostate cancer treatment options, including watchful waiting.
2. Educate patients that they may seek a second opinion from various specialists after diagnosis regarding different treatment options.
3. Educate patients about their right to ask questions regarding the expertise of the provider in treating prostate cancer (e.g., the number of procedures performed, complication rates, etc.)
4. Disseminate information about support groups and other resources for patients diagnosed with prostate cancer and their loved ones.
5. Encourage support for prostate cancer patients throughout treatment.
6. Advocate for funding for the treatment of uninsured patients diagnosed with prostate cancer.

Objective 5:

Monitor research in primary, secondary, and tertiary prevention.

Strategies:

1. Educate men about what it means to participate in clinical trials and observational research in all areas of prostate cancer.
2. Encourage prostate cancer research in primary, secondary, and tertiary prevention, including but not limited to the following:
 - Benefits of screening.
 - Differences in screening in a clinical versus non-clinical setting
 - Improved sensitivity and specificity of screening tools to detect aggressive tumors early and to distinguish those tumors from changes that are not clinically significant.
 - Psychosocial aspects of prostate cancer.
 - Biochemical failure after apparent cure of prostate cancer.
 - Increased focus on minority men and high-risk groups to determine how culture affects screening and treatment decisions.
 - Promotion of accurate health messages and research findings to the general public.
 - Why African-American men are diagnosed at later stages of disease.
 - Risk factors for primary prevention of prostate cancer.

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CHAPTER 12

ORAL CANCER

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ORAL CANCER

Oral cavity and oropharyngeal cancer (hereafter referred to as “oral cancer”) is cancer of the lips, oral cavity, and pharynx and can occur on the tongue, floor of the mouth, soft palate, tonsils, salivary glands, oropharynx, mesopharynx, and hypopharynx. Although oral cancers comprise about 3% of all cancers in the United States, they are more common than leukemia, Hodgkin’s disease, or cancer of the brain, liver, bone, thyroid gland, stomach, ovary, or cervix.¹ The signs and symptoms of oral cancer are shown in Table 12.1.

Approximately 90% of all oral cancers are squamous cell carcinomas—cancers of the epithelial cells—with the remainder being salivary gland tumors and lymphomas. Oral squamous cell carcinomas generally develop after a long latency period from precancerous red-colored erythroplakia or, to a lesser extent, white-colored leukoplakia lesions in the oral mucosa primarily caused by tobacco use alone or in combination with heavy alcohol use.² If not detected early at a localized stage, squamous cell carcinomas can extend into adjacent tissues and metastasize to regional lymph nodes in

the head and neck. Once this extension takes place, oral cancer lesions and their treatment regimen can cause severe disfigurement, pain, and dysfunction affecting speech, chewing, swallowing, and general quality of life. The most common sites for oral cancer development are the ventrolateral (side of the tongue near the back) aspect of the tongue (30% of all oral cancers), lips (17%), and the floor of the mouth (14%).³

Individuals 45 years of age and over comprise more than 90% of all oral cancers with men more likely than women to develop these cancers.⁴ Oral cancers account for 3.1% of all cancers in men compared with 1.6% of all cancers in women.⁵ However, because of changing smoking patterns, the male to female ratio has decreased from 6:1 in 1950 to 1.8:1 in the present.⁶ Further, oral cancers occur more frequently in blacks than in whites.⁷ Blacks are disproportionately affected by oral cancer; it is the fourth most common cancer in black males compared to the tenth most common for all U.S. males, and fourteenth most common among all U.S. women.⁸ Oral cancer mortality rates are also high for U.S. blacks, who experienced nearly twice the mortality rate of U.S. whites in 1998. Oral cancer is the seventh leading cause of cancer death in black men.⁹

Only 18% of blacks with oral cancer in the United States are diagnosed at a local stage compared to 38% for whites.¹⁰ A comparison of regional staging shows higher rates in blacks (56%) than in whites (44%); for distant staging, blacks (13%) have nearly a twofold difference compared with whites (8%).¹¹ A comparison of cancer stage at diagnosis by race in Maryland and the United States is shown in Figure 12.1. Although clinically more visible than most other cancers, and amenable to detection through screening tools such as

Table 12.1
Signs and Symptoms of Oral Cancer

Early

- A sore in the mouth that does not heal (most common symptom)
- A white or red patch on the gums, tongue, tonsil, or lining of the mouth

Late

- A lump or thickening in the cheek
- A sore throat or a feeling that something is caught in the throat
- Difficulty chewing or swallowing
- Difficulty moving the jaw or tongue
- Numbness of the tongue or other area of the mouth
- Swelling of the jaw that causes dentures to fit poorly or become uncomfortable
- Loosening of the teeth or pain around the teeth or jaw
- Voice changes
- A lump or mass in the neck
- Weight loss

Source: American Cancer Society, 2003.

physical observation and palpation, most oral cancers are detected and diagnosed at advanced clinical stages.

Diagnosis of oral cancer at advanced stages is likely responsible for the low survival rate associated with oral cancers relative to other major malignancies. The five-year oral cancer survival rate (56%) has improved little over the past 30 years.^{12,13} The five-year survival rate for early stage oral cancer is 82% but drops to 23% among persons diagnosed with advanced stage cancer. As shown in Figure 12.2, blacks in the United States have disproportionately lower five-year survival rates for oral cancer than whites (35% versus 59%).

Risk Factors

Certain risk factors may increase the chance of developing oral cancer, including the following:

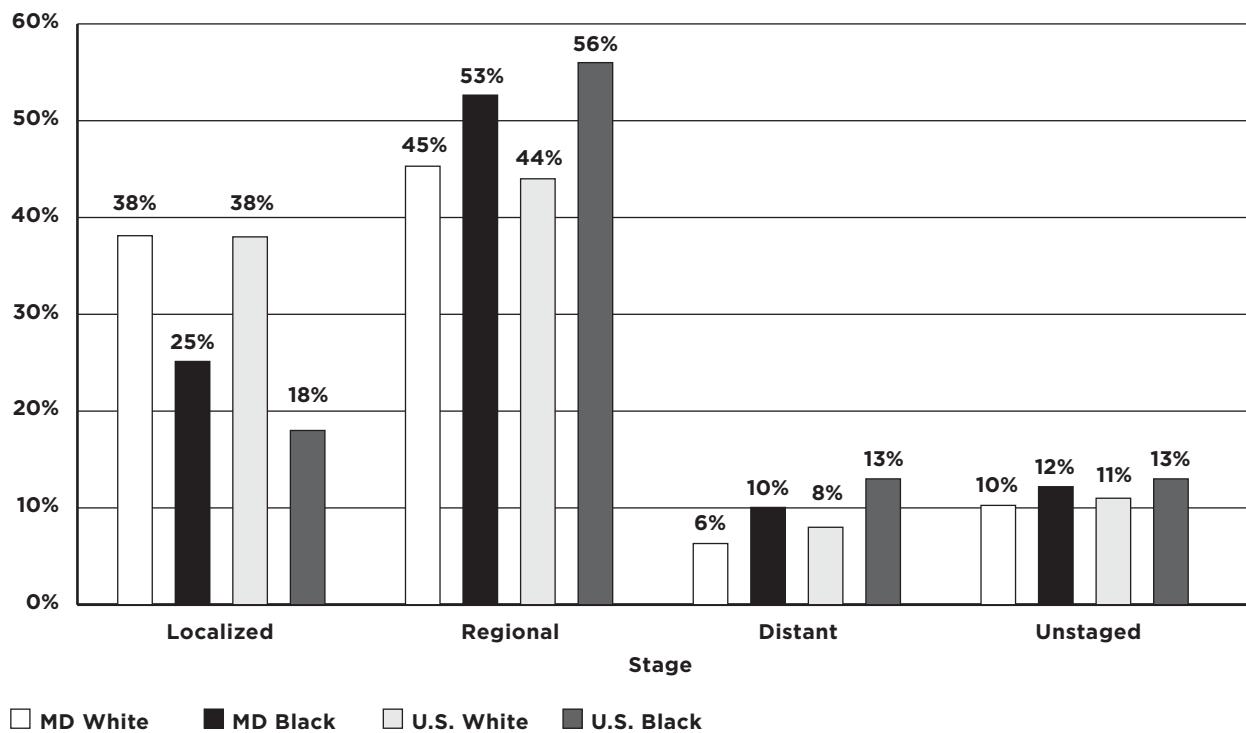
Tobacco and alcohol use

The primary risk factors for oral cancer are past and present use of tobacco products (cigarettes, cigars, pipe and spit tobacco) and alcohol,^{14,15,16} accounting for

75% of all oral cancers. Compared with nonsmokers, smokers have as much as an 18-fold risk of developing oral cancer. African Americans may be especially at risk for oral cancer because of tobacco use. Heavy drinkers who smoke in excess of one pack of cigarettes per day are 24 times more at risk for oral cancer than those who do not use tobacco and alcohol because alcohol is believed to act as a facilitator for the penetration of the tobacco carcinogens into the soft tissues of the mouth. In addition, recent evidence indicates that marijuana use may also increase the oral cancer risk.¹⁷

The role of spit tobacco in oral squamous cell carcinoma development is less clear than other forms of tobacco because of confounding factors from concurrent tobacco and alcohol use and the different patterns of spit tobacco use.^{18,19} However, various national and international agencies and advisory committees have concluded that the many forms of spit tobacco, including snuff, do play a role in oral cancer development.²⁰ Paan, bidis, and betel or areca nut use, behaviors specific to Southeast Asia but growing in the United States,

Figure 12.1
Oropharyngeal Cancer Stage at Diagnosis by Race in Maryland and the United States, 1992-1997



Source: Maryland Cancer Registry, 1992-1997; SEER, National Cancer Institute, 1992-1997.

have been found to give rise to submucous fibrosis, a precancerous condition consisting of generalized fibrosis of the oral soft tissues.^{21,22,23}

Sun exposure

Exposure to UV radiation increases the risk of lip cancer.²⁴

Viral etiology

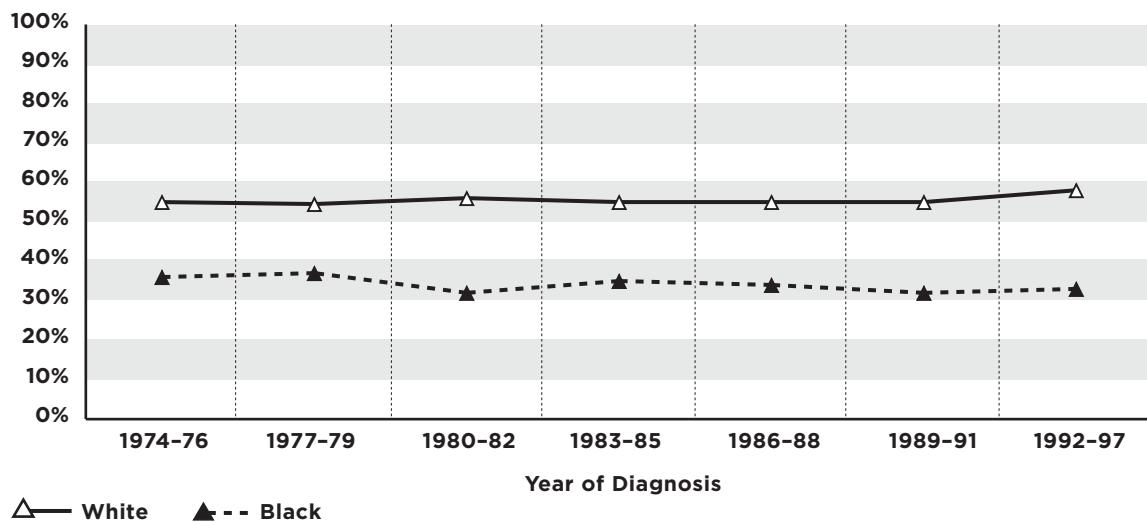
Exposure to viruses such as human papillomavirus (HPV), herpes simplex type 1, and the Epstein-Barr virus (EBV) are also risk factors.^{25,26} Viruses are capable of producing cancer-causing genes called oncogenes. Many oncogenes have been found in oral cancers and are thought to develop through an array of genetic mutations and alterations. HPV has been isolated in both oral precancerous and squamous cell carcinoma lesions and also is known to act as co-factor in carcinogenesis development in both cervical and oral cancers.^{27,28} Various herpes virus types have been discovered in oral cancers including Kaposi's Sarcoma, a rare cancer found in AIDS patients that is often first detected in the oral cavity.^{29,30} In addition to these viruses acting as etiologic agents in oral cancer development,

fungal infection caused by strains of *Candida albicans* may possibly cause oral cancer through the development of carcinogenic nitrosamines in the oral soft tissues.³¹

Diet

Poor dietary intake of essential nutrients found in fruits and vegetables may also be a risk factor for oral cancer.³² The intake of an appropriate amount of fruits, vegetables, and dietary fibers may afford a protective effect against early oral cancers and precancerous lesions, especially among smokers. For example, it is believed, that Plummer-Vinson syndrome, which causes iron deficiency anemia in women, may place women at risk for oral cancer.³³ In addition, the role of antioxidants, including vitamins A, C, and E, dietary selenium, folate, and certain carotenoid and retinoid compounds, is currently being studied. If such a link is definitively established, nutrient ingestion could play a major role in preventing oral cancer development.^{34,35}

Figure 12.2
Five-Year Relative Survival Rates Following Diagnosis by Race
for Oropharyngeal Cancer in the United States, 1974-1997



Source: SEER, National Cancer Institute, 1974-1997.

Burden of Oral Cancer in Maryland

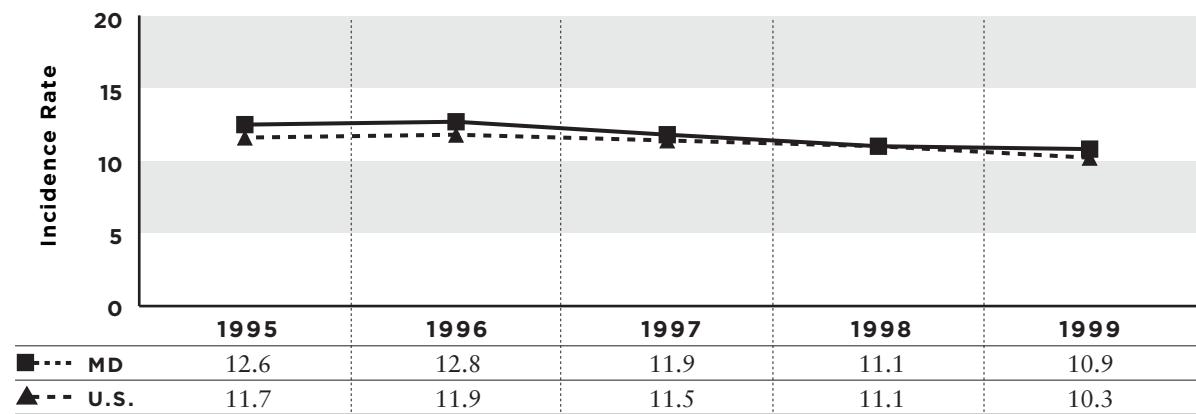
The oral cancer mortality rate in Maryland is among the highest (eighth) in the United States and ranks fifth for black males. The rate of new oral cancer cases in Maryland has decreased since 1995 but remained higher than the national average in 1999 (Figure 12.3). Maryland's oral cancer death rate, which has historically been higher than the nation's, was still above the national rate in 1999, but has been decreasing slowly since 1995 (Figure 12.4). There were 539 new cases of oral cancer in Maryland in 1999 with 144 oral cancer deaths (Table 12.2).

In general, oral cancer incidence rates for all races and sexes in Maryland slightly decreased from 1995-1999 and are fairly comparable to national rates. Maryland blacks had a higher oral cancer incidence rate than Maryland whites in 1999 (11.7 versus 10.4 cases per 100,000 persons) and Maryland males have approximately a 2.5 times higher incidence rate than Maryland females (Table 12.2). As shown in Figure 12.5, black men in Maryland experience the highest oral cancer incidence rate of any racial and gender group. Blacks in Maryland are disproportionately affected by oral cancer, it being the fifth most common cancer in black males compared to the seventh for white males.³⁶ White and black males in Maryland have slightly lower incidence rates than the national average while the oral cancer inci-

dence rates of women of both races in Maryland are slightly higher than the national average. Similar to national trends, the highest age-specific oral cancer incidence rates occur in a younger black age cohort (60-64 years old) than their comparable white age cohort (75-79 years old). Males and females 65 years and older experience the highest rates of new oral cancer cases in Maryland.³⁷

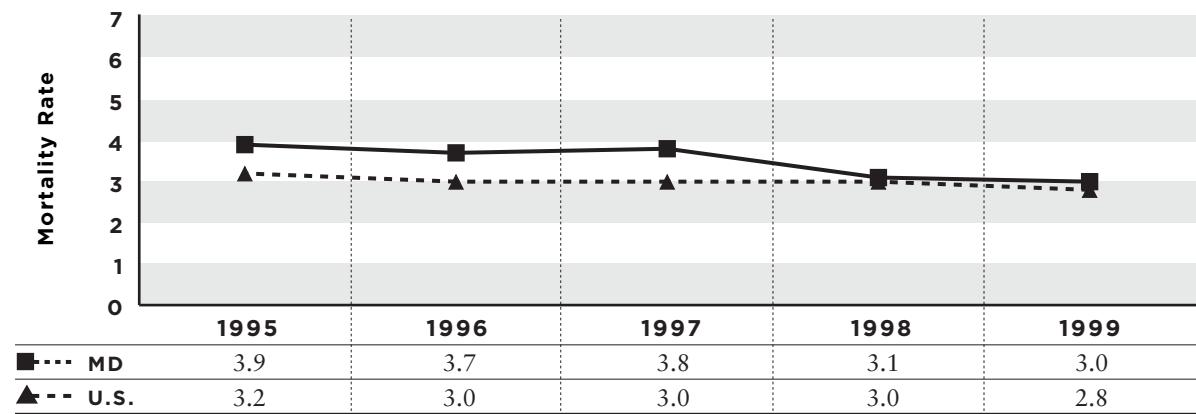
Blacks experience the highest oral cancer mortality rates in Maryland. However, as shown in Figure 12.6, there was a considerable reduction in the oral cancer mortality rates for blacks between 1995 and 1999 and the Maryland rate for blacks is now lower than the national rate for blacks. While demonstrating less of an improvement than blacks, the oral cancer mortality rate for Maryland whites has also decreased and is nearing the national rate. Similar to national trends, Maryland's oral cancer mortality rates for males are about 2.5 times higher than those for females.³⁸ While Maryland mortality data by race and sex are not available due to small sample size, it is likely that the trend in death rates according to race and sex is similar to the national data. This indicates that black males have twice the oral cancer mortality rates than their white peers and have the highest oral cancer mortality rates of any racial or gender group (Figure 12.7) Similar to national trends, blacks in Maryland also appear to experience higher mortality rates at a younger age with almost a fivefold higher difference in mortality than

Figure 12.3
Oropharyngeal Cancer Incidence Rates in Maryland and the United States, 1995–1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995–1999; SEER, National Cancer Institute, 1995–1999.

Figure 12.4
Oropharyngeal Cancer Mortality Rates in Maryland and the United States, 1995–1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995–1999; SEER, National Cancer Institute, 1995–1999.

whites for the 50–54 age cohort.³⁹

Oral cancer incidence and mortality rates varied by Maryland region in 1995–1999 (Table 12.3). The southern region, Eastern Shore, and Baltimore metropolitan area had the highest rates of new oral cancer cases. The oral cancer incidence rate for the Eastern Shore was statistically significantly higher than the Maryland rate, while the incidence rate for the national capital area was statistically significantly lower than the state's rate. The southern region, Eastern Shore, and Baltimore metropolitan area also had the highest mortality rates in the state but these rates were not statistically significantly higher than the Maryland rate.

Disparities

Blacks clearly bear a disproportionate share of the oral cancer burden in Maryland with respect to incidence, mortality, stage at diagnosis, and five-year survival rate when compared to their white peers. This disparity in oral cancer burden likely is related to the disparity in access to oral health care that exists between blacks and whites from Maryland. While access to oral health care in Maryland is not the focus of this chapter, it clearly looms as a significant impediment to this population receiving routine oral cancer examinations to facilitate early diagnosis and detection practices. Major disparities include:

Table 12.2
Oral Cancer Incidence and Mortality By Race and Sex
in Maryland and the United States, 1999

Incidence 1999	Total	Males	Females	Whites	Blacks
New Cases (#)	539	372	167	381	132
Incidence Rate	10.9	16.5	6.2	10.4	11.7
U.S. SEER Rate	10.3	15.2	6.3	10.1	11.8
Mortality 1999	Total	Males	Females	Whites	Blacks
MD Deaths (#)	144	98	46	100	43
MD Mortality Rate	3.0	4.7	1.7	2.7	4.1
U.S. Mortality Rate	2.8	4.2	1.6	2.6	4.4

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

- Oral cancer lesions in blacks are more likely to be diagnosed at a regional and distant stage than whites.
- Black men have the highest oral cancer incidence and mortality rates of any race and sex; black males have twice the oral cancer mortality rate than white males.

Primary Prevention

Primary preventive efforts in tobacco prevention and cessation are essential and should not be overlooked as preventive measures for oral cancer. These efforts are discussed in further detail in chapter 5, Tobacco-Use Prevention and Cessation and Lung Cancer.

Oral Cancer Examination

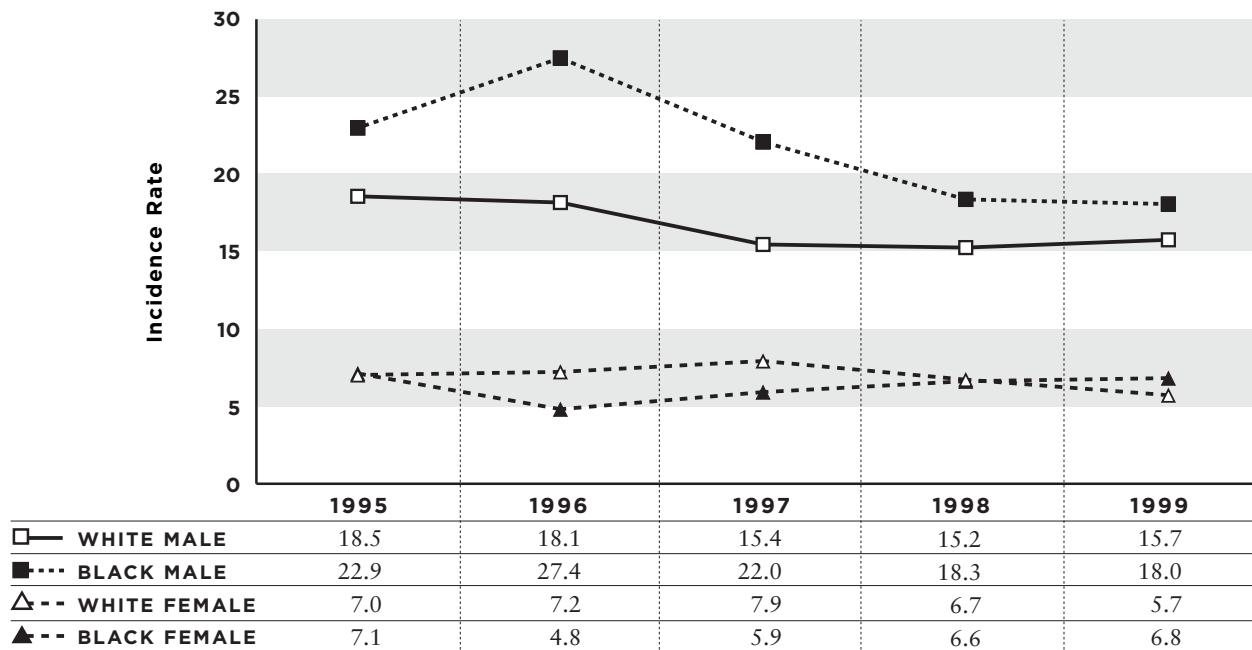
The incorporation of routine oral cancer examinations (and other screening methodologies for oral cancer) into the daily practice of health care practitioners can increase the likelihood of earlier detection of lesions at a more localized stage. However, there is no evidence that such early detection can decrease mortality⁴⁰ even though five-year survival rates are higher when lesions are diagnosed at an earlier stage. The American Cancer Society has determined that for the years 1992–1997, the five-year survival rate for oral cancer lesions diagnosed at a local stage was 82% compared to 46% and 21% survival for regional and distant staging, respectively.⁴¹

Thus, in the absence of science-based evidence from clinical trials which are difficult to implement in the U.S., routine early detection should still be recommended because:

- oral cancer is a serious yet treatable disease in its early stages
- treatment in the early stages of oral cancer is generally acceptable to asymptomatic patients and provides benefits compared with later treatment of symptomatic patients
- the screening examination is inexpensive and safe.⁴²

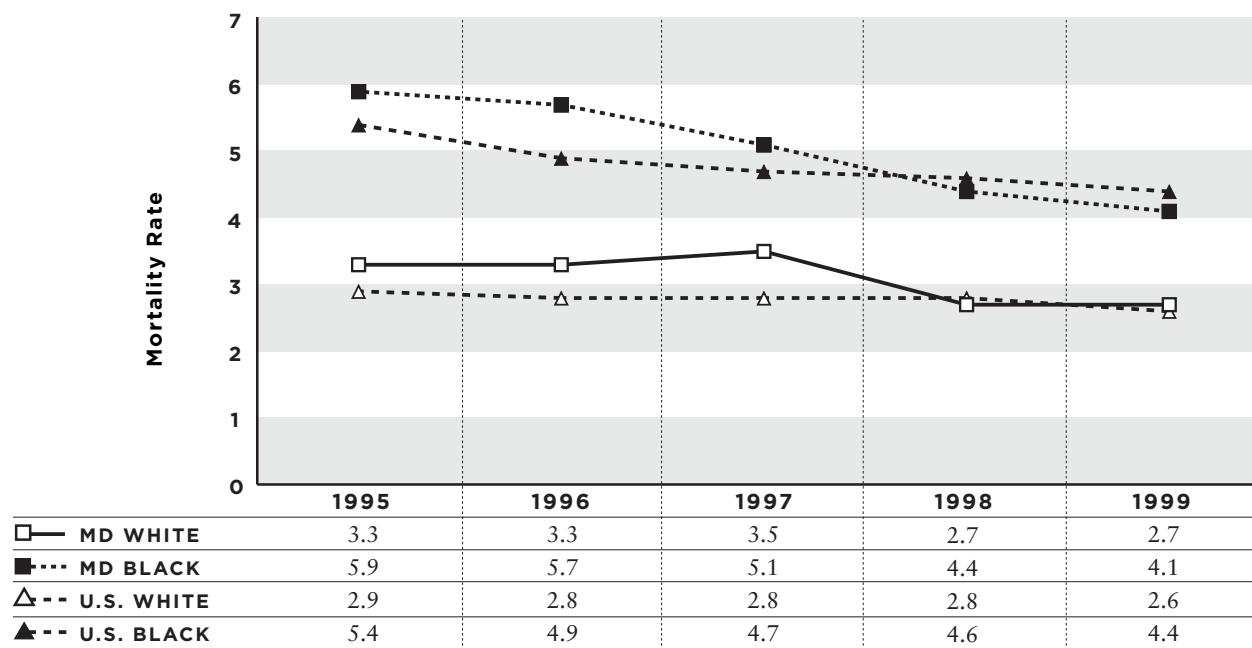
Secondary prevention of oral cancer incorporates a number of screening tests but foremost among them is the oral cancer examination which entails the visual assessment and manual palpation of extraoral head and neck areas, perioral and intraoral soft tissues, and dental and periodontal tissues.⁴³ The oral cancer examination can be performed easily in no more than two minutes by a health care practitioner because the oral cavity and accompanying head and neck region is easily accessible.⁴⁴ Further, the examination is noninvasive and causes little discomfort and no embarrassment compared with other cancer screening interventions. Although dentists and dental hygienists are the ideal health practitioners to perform this type of examination, other health care providers (i.e. nurse practitioners, nurses, physician assistants, physicians) can assume more responsibility in providing oral cancer examinations as part of routine physical examinations. Non-dental health care providers may be critically

Figure 12.5
Oropharyngeal Cancer Incidence Rates by Race and Sex in Maryland, 1995-1999



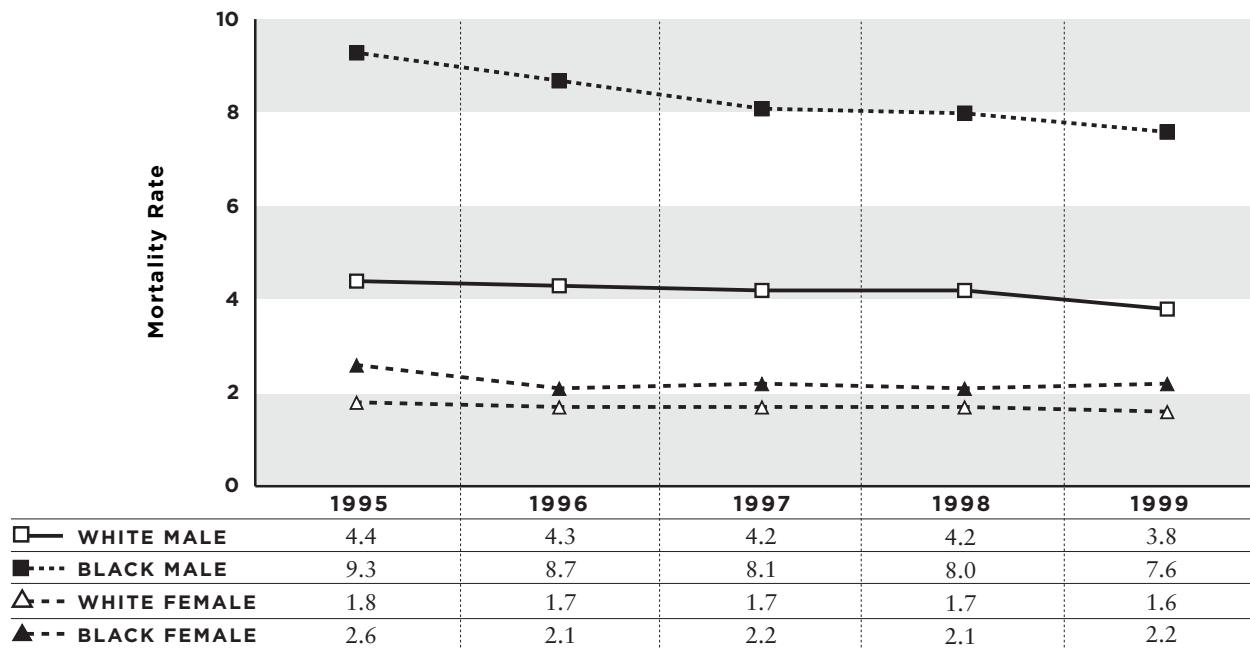
Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995-1999.

Figure 12.6
Oropharyngeal Cancer Mortality by Race in Maryland and the United States, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 12.7
**Oropharyngeal Cancer Mortality Rates by Race and Sex in the United States,
 1995-1999**



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: SEER, National Cancer Institute, 1995-1999.

important to these screening efforts because individuals at high risk for oral cancer are more likely to visit these providers than a dentist or dental hygienist.

First, a careful health history must be completed, assessing risk factors such as past and present tobacco and alcohol use, diet and lifestyle, prior cancer history, sun exposure experience and behaviors, surgeries and medications, and even sexual practices to discern possible HPV exposure.⁴⁵ Next, the examination should include the assessment of clinical signs of lesions and the presence and shape of palpable lymph nodes. The health-care practitioner should assess any craniofacial abnormalities and then assess and palpate for lymph nodes in known head and neck areas as well as the many salivary glands that are present. In addition, extraoral and intra-oral color, texture, size, contour, or symmetry change should be noted by the examiner.⁴⁶ This is accomplished by systematically assessing and palpating the lips, and then assessing the soft tissues of the mouth including upper and lower labial mucosa, buccal (cheek) mucosa, gingival tissues (gums) in both upper and lower jaws, tongue and floor of the mouth, hard and soft palate, and the tonsillar and oropharyngeal (throat) region. Special attention must be given to the high risk oral cancer areas of the mouth, that is, the lateral borders of the

tongue, lips, and floor of the mouth.⁴⁷

Two technologies which may aid identification and diagnosis of oral malignancies are toluidine blue stain and the chemoluminescent light.⁴⁸ Toluidine blue is a fast and easy office procedure used to stain suspected malignant tissue, especially when several surface abnormalities are present. Tissue that stains blue indicates either dysplasia or malignancy. The chemoluminescent light was recently approved for oral mucosal screening by the Food and Drug Administration based upon its successful use in cervical cancer screening.⁴⁹ The chemoluminescent light is directed to oral mucosal tissue previously rinsed with dilute acetic acid to detect an opaque-like alteration, which may be indicative of malignant change. These two agents may be very useful to identify lesions that may require biopsy.⁵⁰

A subtle change in the areas examined may indicate an early suspicious lesion that should receive follow-up attention. Generally, early lesions are small (less than 1.0 cm) with minimal, if any, extension into the underlying tissues, ill-defined, not easily visible, and most importantly, asymptomatic.⁵¹ If the practitioner believes that the lesion may be a possible malignancy, or if the patient is in need of a definitive diagnosis as

Table 12.3
Oral Cancer Incidence and Mortality by Region in Maryland, 1995-1999

Region	Incidence Rate	Mortality Rate
Maryland	11.8	3.5
Baltimore Metropolitan	12.6	3.7
Eastern Shore	13.9 +	3.8
National Capital	9.8 -	3.0
Northwest Region	10.7	3.1
Southern Region	13.8	4.4

"-" Denotes regions statistically significantly lower than the Maryland rate.

"+" Denotes regions statistically significantly higher than the Maryland rate.

Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.

Source: Maryland Cancer Registry, 1995-1999; Maryland Division of Health Statistics, 1995-1999.

soon as possible, the patient should be referred for scalpel or punch biopsy for diagnosis, and if malignant, the stage and grade. Another technology which has recently emerged to assist the health care practitioner more accurately discern whether a lesion may be a malignancy, or whether a punch or scalpel biopsy is indicated, is the brush biopsy.⁵² The brush biopsy technique is relatively simple to perform in any health care environment using a small stiff-bristled brush to collect mucosal epithelial cells from a suspicious site and immediately place and fix the tissue on a slide. The slide is subsequently sent to a laboratory for computer analysis with the results sent back to the practitioner within a week. However, even with the use of these adjunctive measures, a definitive diagnosis through incisional biopsy is mandatory.⁵³

Screening Recommendations of Professional Groups

A few prominent task forces and organizations have developed guidelines for oral cancer screening (Table 12.4) but the lack of consensus among these groups has failed to provide clear direction for health care practitioners and the public.^{54,55,56} Since the appropriate clinical trials to assess the effectiveness of early detection in reducing oral cancer mortality have not been executed, the major preventive services task forces in the United States and Canada^{57,58} have determined that there is not enough evidence to recommend routine oral cancer screenings except for those patients at high risk. It should be noted, however, that the most recent task force statement on this issue states clearly that this does not mean that such examinations are not effec-

tive.⁵⁹ The American Cancer Society recommends routine oral cancer screening for all patients as part of the periodic dental examination and also recommends that primary care physicians assess the oral cavity as part of their routine cancer examination.⁶⁰

The American Cancer Society recommendations are important because they recognize that individuals at high risk for oral cancer, including those with low income, lacking health insurance, with less than a high school education, 65 years of age or older, and of minority group status, are more likely to visit a physician than a dentist.⁶¹ This is because most state Medicaid programs do not provide comprehensive dental coverage for adults and Medicare does not cover routine dental services, including screening for oral cancer. Thus, there is less opportunity for routine inspection of the oral cavity for these high-risk groups, which in itself may exacerbate the problem.

The recommendations of the various U.S. and Canadian preventive task forces presume that health care practitioners readily and knowingly assess whether a patient is at high risk for oral cancer through a careful and comprehensive health history that requests information on high risk behaviors. All major health organizations, including the American Dental Association, encourage dental practitioners' assessment of high risk behaviors by including questions on tobacco use in their respective medical history forms. However, studies have shown that clinicians either do not adequately assess or are unaware of patients' high risk behaviors. For example, approximately one third of Maryland dentists did not ask about present use of alcohol and 23% of these respondents failed to inquire about past history of tobac-

Table 12.4**Oral Cancer Screening Guidelines of Professional Organizations^{61,62,63,64}**

Organization/ Taskforce	Effectiveness	Recommendation
American Cancer Society, 2003	Many cancers of the oral cavity and oropharynx can be found early, during routine examinations by a doctor or a dentist, or by self-examination.	Regular checkups that include an examination of the entire mouth are important in the early detection of oral and oropharyngeal cancers and pre-cancerous conditions. The ACS also recommends that primary care doctors examine the mouth and throat as part of a routine cancer-related checkup.
Canadian Task Force on Preventive Health Care, 1999	The usefulness of screening is limited by the low prevalence and incidence of disease, the potential for false diagnosis, and the poor compliance with screening and referral. No studies have shown that screening intervention programs reduce mortality or morbidity due to oral cancer.	<p>Population Screening: Fair evidence to exclude the general population for oral cancer by clinical examination.</p> <p>Opportunistic Screening: Insufficient evidence to recommend inclusion or exclusion of screening for oral cancer by clinical examination.</p> <p>For high risk patients, annual examination by physician or dentist should be considered. Major risk factors include a history of tobacco use and excessive alcohol consumption.</p>
U.S Preventive Services Task Force, 1996	Despite the strong association between stage at diagnosis and survival, there are few controlled data to determine whether routine screening in the primary care setting leads to earlier diagnosis or reduced mortality from oral cancer.	There is insufficient evidence to recommend for or against routine screening of asymptomatic persons for oral cancer by primary care clinicians. Although direct evidence of a benefit is lacking, clinicians may wish to include an examination for cancer and pre-cancerous lesions of the oral cavity in the periodic health examination of persons who chew or smoke tobacco (or did so previously), older persons who drink regularly, and anyone with suspicious symptoms or lesions detected through self-examination.

Table 12.4 (Cont.)**Oral Cancer Screening Guidelines of Professional Organizations^{61,62,63,64}**

Organization/ Taskforce	Effectiveness	Recommendation
Task Force on Community Preventive Services, 2001	No studies met the minimum quality criteria for assessing effectiveness in increasing detection of cancers and precancers, improving health status, or reducing mortality.	Insufficient evidence for community-wide, coordinated public education, professional education and training, professional examination of persons at high risk in various settings (e.g., home, health fairs, field clinics, usual source of care), and referral of persons with suspicious lesions (e.g., erythroplakia, leukoplakia, lichen planus, submucous fibrosis, and oral cancer) for follow-up and treatment.

co use and the types and amounts used.⁶⁶ Further, a study assessing health history forms used in U.S. and Canadian dental schools found that the health history did not adequately assess high risk behaviors linked to oral cancer.⁶⁷

Examination Rates

A national survey conducted in 1992 (National Center for Health Statistics Cancer Supplement Survey) found that 13% of U.S. adults age 40 or older had ever received an oral cancer examination and only 7% had received one in the past year.⁶⁸ This study further found that those individuals least likely to receive an oral cancer examination were adults with lower educational backgrounds. Another national survey of dentists found that 19% did not provide an oral cancer examination to all their patients 40 years and above and that 88% of dentists did not provide an oral cancer examination to their edentulous patients (those without teeth), a group known to be at high risk for oral cancer.⁶⁹ Similar results were found for the rate of oral cancer examinations provided by dental hygienists.⁷⁰

Maryland dentists reportedly provided an oral cancer examination for the vast majority of their patients ages 40 and above but only 6% reported conducting this examination for their edentulous patients.⁷¹ Further, 40% of Maryland dentists did not perform a comprehensive oral cancer examination for the majority of their

patients because they neglected to palpate for lymph node involvement.

A 1996 survey of Maryland adults age 40 and over found similarly low oral cancer examination rates, although they were somewhat higher than U.S. rates.⁷² In addition, the survey found that those at high risk for oral cancer were least likely to have received an oral cancer examination. Approximately 20% of Maryland adults reported receiving an oral cancer examination in the past year and 28% reported that they had ever received such an examination in their lifetime. African Americans received significantly fewer oral cancer examinations (14.2%) than whites (32.2%), and those with more than a high school education (32.1%) were significantly more likely to receive an oral cancer examination than those with less than a high school education (23.2%). Finally, those who smoked cigarettes every day were significantly less likely to receive an oral cancer examination (16.4%) than those who smoked on some days (24.2%) and those who didn't smoke at all (31.4%).⁷³ The survey questions were comparable to those asked in the national survey and specifically asked if the patient recalled the health care practitioner pulling out their tongue with a piece of cotton gauze and inspecting it from side to side. While recall bias always plays a role in these types of surveys, the responses were likely valid given the vivid description of the tongue examination.

Recent data from the Maryland Cancer Survey sug-

gests that since 1996, the proportion of Marylanders who have received an oral cancer examination has improved significantly.

In 2002, 33.9% of Marylanders age 40 and over reported that they had received an oral cancer examination in the last year (Figure 12.8).⁷⁴ In addition, 42.8% of adults age 40 and over reported that they had received an oral cancer exam at least once in their lifetime.⁷⁵ Despite this progress, there remains considerable room for improvement regarding the proportion of Marylanders who receive oral cancer examinations.

Barriers to Oral Cancer Examination

In addition to the lack of consensus in oral cancer screening guidelines, the low examination rates described here are due to a number of significant financial, educational, and behavioral barriers. These barriers include lack of access to dental care services as well as a lack of oral cancer knowledge that likely affects behaviors of both the public and health care practitioners in the U.S. and Maryland.

Lack of Access to, and Utilization of, Oral Health Services for High Risk Populations

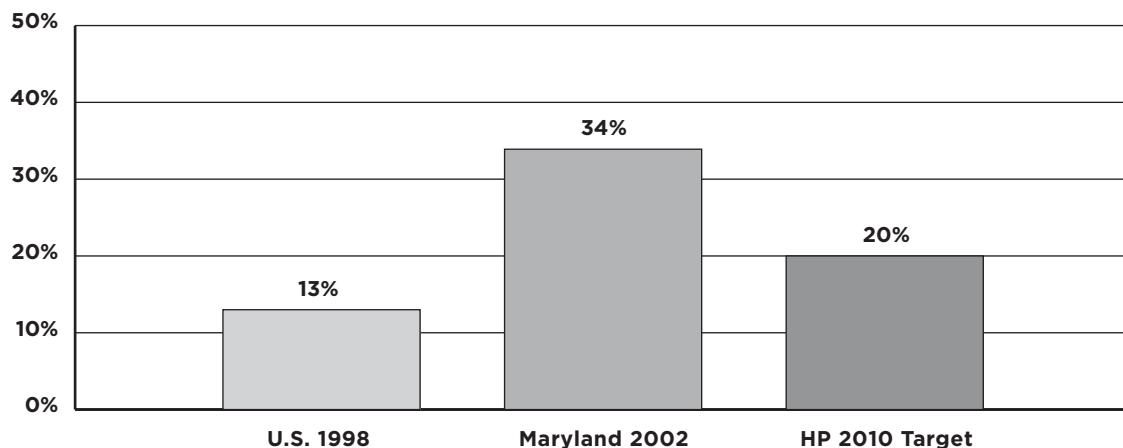
Oral Cancer Early Detection and Diagnosis Services

For those at highest risk for oral cancer access to the health care system is limited in Maryland and is a crit-

ical issue in the receipt of timely and appropriate oral cancer examinations. It is well established that those populations with the highest oral cancer mortality rates experience the poorest access to the overall health care system.⁷⁶ Populations at high risk for oral cancer with restricted access to the health care system include the following characteristics: minority status, low income, low education, no health insurance, and 65 years of age or older. Unfortunately, their access to dental care services is even more limited.

Although Medicare covers costly surgical procedures for oral and pharyngeal cancer, it does not cover inexpensive and routine dental procedures *including oral cancer examinations*. Like most states, Medicaid dental coverage in Maryland for adults 65 years and younger is very limited and is unavailable to patients more than 65 years of age. As a result of these restrictions, populations at risk for oral cancer are more likely to visit a physician than a dentist and the frequency of visits to physician offices is far greater than it is to dental practices.⁷⁷ Therefore the best opportunity for these populations to receive an oral cancer examination may be during a routine visit to non-dental health care practitioners such as physicians, nurse practitioners, and physician assistants. Yet studies in Maryland show that non-dental health care practitioners are not using this occasion to provide oral cancer examinations to their high-risk patients. While 28% of Maryland residents reported receiving an oral cancer exam, 70% were provided by either a dentist (64%) or dental hygienist (6%) during a routine dental visit and only 22% were provided as part of a routine physical

Figure 12.8
Oral Cancer Screening Within the Past Year



examination.⁷⁸ Despite these findings, the studies showed that physicians diagnosed more oral cancers than dentists and that the majority of these malignancies were detected at a late stage in their development.⁷⁹

Coverage of medically necessary dental procedures that could facilitate the provision of oral cancer examinations for adults with no dental insurance is generally difficult to obtain in most health care benefit packages. Often these claims are judged on a case-by-case basis and variably successful even with a strong physician advocate. While tertiary care for advanced oral cancer cases can be obtained through most medical insurance packages, the opportunity for cost-efficient primary or secondary preventive care for this disease is missed because of the lack of this coverage.

Oral Cancer Treatment and Referral Services

Generally, oral cancer treatment services can be accessed through private or public medical insurance packages. However, these services are usually unavailable for uninsured adults not yet eligible for Medicare. Further, once a lesion is detected or suspected of being malignant through oral cancer examination, many patients experience difficulties in obtaining more invasive diagnostic services such as scalpel or punch biopsy. The referral systems for these services are often small and random, if present at all, providing additional continuity problems for those patients who eventually will need treatment.

Lack of Oral Cancer Literacy among the Public, Health Care Practitioners, Policymakers, and the Media

Healthy People 2010 defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”⁸⁰ Based on studies assessing the knowledge and attitudes of the public and health care practitioners in the U.S. and Maryland, the oral cancer literacy of these groups appears to be less than what is needed for informed decisions and behaviors.

Studies conducted in the U.S. and Maryland show that the public is not well informed about oral cancer and its prevention. Only 23% of the Maryland public could identify an early oral cancer symptom and only 21% were aware that there was an examination or test for oral cancer.⁸¹ While most respondents correctly

identified tobacco as an oral cancer risk factor, only 13% knew that alcohol also was a major risk factor for this cancer. Similar low responses were given for other oral cancer risk behaviors.⁸²

A pilot study conducted in Maryland found that dentists were not as knowledgeable regarding oral cancer prevention as they thought and that most physicians did not believe that their oral cancer knowledge was current.⁸³ The oral cancer knowledge base of these practitioner groups was found to play a significant role in their related examination behaviors. While the vast majority of dentists were providing oral cancer examinations, a high proportion of these examinations likely were not performed appropriately. Further, it was found that those physicians who did not believe their oral cancer knowledge to be current were less likely to provide routine oral cancer examinations.⁸⁴

More representative, broad-based studies of Maryland dentists and dental hygienists corroborated the findings of the earlier pilot study. However, they also found that these health care providers did not feel adequately trained to palpate lymph nodes as part of their oral cancer examination and that providers were not examining high-risk edentulous patients.^{85,86} While knowledgeable in other aspects of oral cancer prevention, only 16% of dental hygienists knew that the majority of oral cancer lesions were diagnosed in patients over the age of 60. The same low proportion of dental hygienists knew that erythroplakia and leukoplakia were the conditions most associated with oral cancer.⁸⁷ Similar findings of low oral cancer knowledge were found for non-dental health providers such as family physicians and family nurse practitioners.^{88,89} They possessed a low knowledge base included oral cancer risk factors, signs and symptoms, and the most common sites where oral cancer lesions are found. The majority of family physicians (64%) were interested in enhancing their oral cancer knowledge base through continuing education courses while over 80% of family nurse practitioners reported that their oral cancer knowledge was not current.^{90,91}

In addition to helping the Maryland public have greater knowledge and understanding about oral cancer, it is vital that the public become functionally literate in obtaining appropriate health services. All health-related intake forms (e.g., Medicaid and Medicare) must be written in plain language that can be understood by their intended audience. In addition, the use of “smart cards,” which reduce paperwork for providers and increase the transfer of confidential information, will aid this process. Further, health

care providers must receive training to improve their communications skills so as to increase patient comprehension and encourage patients to play a more active role in their own health care and maintenance.

Although Maryland is fortunate to have several legislators who are keenly aware of the oral cancer problems in Maryland, generally, there is little awareness of oral cancer, relative to other cancers, among policymakers. The overall lack of knowledge and understanding among policymakers, the public, and the media impacts the development of oral cancer initiatives and programs.

Lack of Research

Evidence-based clinical trials for oral cancer prevention modalities that demonstrate a definitive impact on morbidity and mortality rates have not been conducted because of logistical concerns and lack of funding. Specifically, research that assesses screening effectiveness is critically needed if an institutional application of known oral cancer prevention modalities is to be accomplished. In the absence of such research, oral cancer prevention guidelines and protocols will continue to lack consensus and ultimately guidance for the public, health care practitioners, policymakers, and health care delivery systems.

More evidence-based information is needed to evaluate and compare the practice patterns of primary care and dental providers, and to assess the effectiveness of existing oral cancer prevention programs. Currently, funding to expand ongoing oral cancer research and the development of more sensitive and specific oral cancer screening tools is limited. Additional resources are needed for this and for research that aids our understanding of the etiologic pathways from potential viral, environmental, behavioral, and familial sources.

Ideal Model for Oral Cancer Control

An Oral Cancer Prevention, Early Detection, and Treatment Model was developed to increase the oral cancer literacy of specific groups. The end products of improving oral cancer literacy are more routine, timely, and comprehensive oral cancer examinations that are requested by an informed public and adequately provided by informed dental and non-dental health care practitioners. Further, an informed and engaged media will enhance oral cancer knowledge and awareness among all groups, including policymakers, who

can craft their own impact on oral cancer prevention through legal, educational, scientific, fiscal, and curricular change. The increase in appropriate oral cancer examination, referral, follow-up, and related treatment efforts, coupled with expansion of media awareness and policy change, should lead to reduced oral cancer morbidity and mortality in Maryland and a significantly smaller disparity in these rates between African Americans and whites.

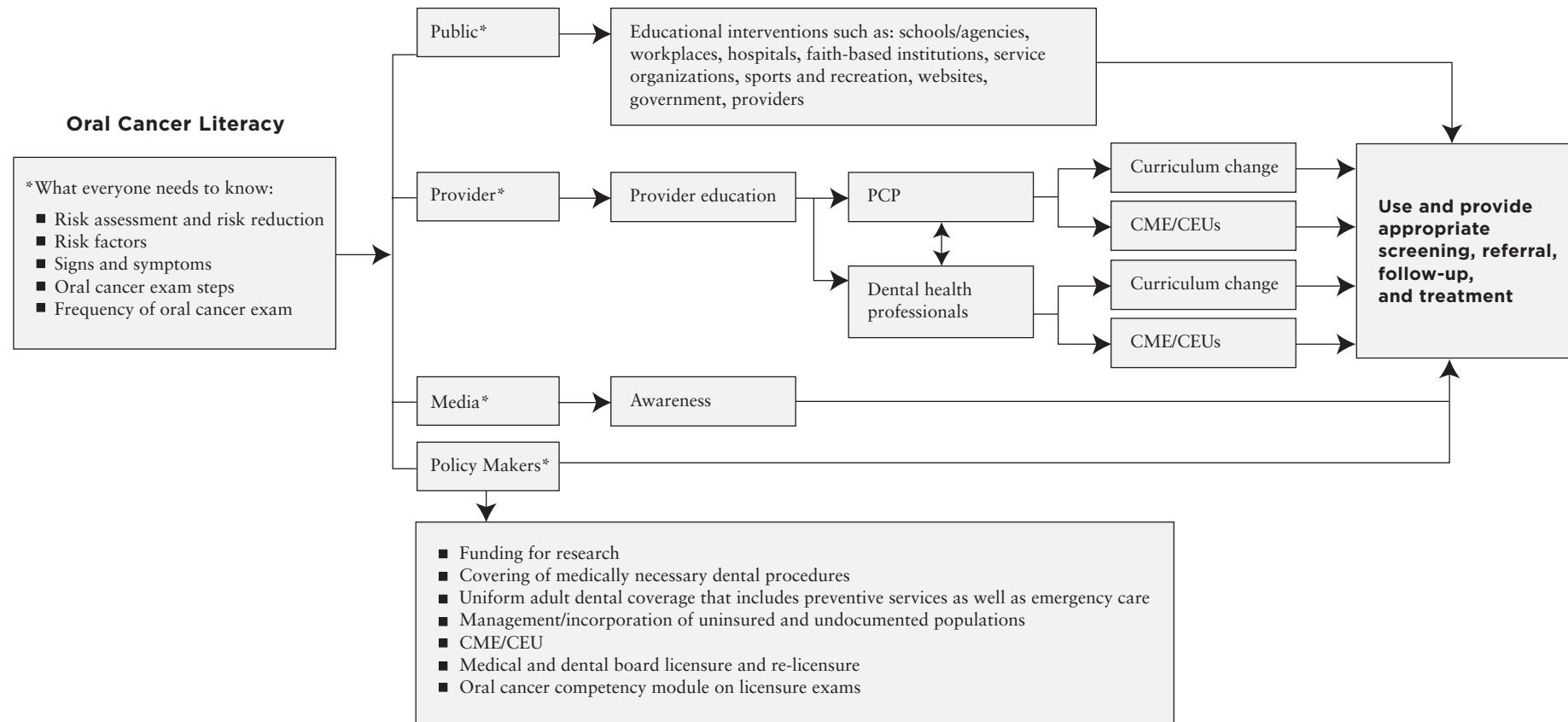
As described in Figure 12.9, oral cancer literacy entails the attainment of knowledge of oral cancer prevention measures by the target populations (the public, health care providers, the media, and policymakers). Such knowledge includes an understanding and awareness of oral cancer risk assessment and reduction, risk factors and behaviors, signs and symptoms, and the rudiments and frequency of adequate and timely oral cancer examinations. The public needs to be specifically targeted for these messages through appropriate venues while dental and non-dental provider education must be enhanced through wider availability of oral cancer continuing education courses and curricular change. These public and health care provider strategies should increase the number of appropriate oral cancer examinations and related referral, follow-up, and treatment modalities.

The oral cancer literacy of the media must be enhanced so it can facilitate awareness for other targeted groups and facilitate the provision of oral cancer prevention strategies. It is particularly important that the media (and other information systems) target policymakers as they can help achieve long-term change through direct influence on legal, educational, curricular, fiscal, research, and health service access issues that impact oral cancer literacy and its effects.

Current Efforts in Maryland

In recognition of many of the problems previously described, a small partnership of disparate groups developed in the early 1990s to attempt to reduce the high rates of oral cancer morbidity and mortality in Maryland and to reduce the disparity in oral cancer rates between whites and African Americans.⁹² The partnership included the American Cancer Society; the National Institute of Dental and Craniofacial Research (NIDCR); the Department of Health and Mental Hygiene (DHMH); the University of Maryland Dental, Medical, and Nursing Schools; professional health organizations representing dentists, dental hygienists, family nurse

Figure 12.9
Oral Cancer Prevention, Early Detection, and Treatment Model



Source: Developed by the Oral Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

Table 12.5
Action Steps for Oral Cancer Prevention and Early Detection

3 Phases:

Needs Assessment

- Review of state epidemiologic data.
- Surveys of knowledge, opinions, and practices of the public.
- Surveys of knowledge, opinions, and practices of health care practitioners.
 - Dentists
 - Dental Hygienists
 - Family Nurse Practitioners
 - Family Physicians
- Disseminate findings of surveys.

Develop and Pilot Test Educational Interventions

- Develop educational intervention(s) and pilot test public and health care providers.
- Develop, test, and produce educational materials.
- Implement educational interventions.

Program Evaluation

- Review of state epidemiologic data.
- Surveys of health care providers and public.
- Prepare publications/reports—disseminate.
- Readjust educational interventions based on program evaluation.
- Use findings for program revision and for establishment of needed policies.

Source: National Institute of Dental and Craniofacial Research, 2000.

practitioners, and family physicians; local health departments; local churches; and the Department of Veterans Affairs.⁹³

The early efforts of this partnership encompassed educational, networking, and advocacy activities with many target populations throughout Maryland to enhance awareness, knowledge, and understanding about oral cancer. Their actions eventually led to two important outcomes that helped advance oral cancer awareness in Maryland: (1) inclusion of two oral cancer prevention objectives in the Maryland Health Improvement Plan and (2) inclusion of oral cancer as one of seven targeted cancers in the state's Cigarette Restitution Fund (CRF) program. For example, Baltimore City and Montgomery County have been very active in providing oral cancer screenings, training providers, and developing educational materials. The African American Health Initiative's Oral Health Coalition in Montgomery County has focused on providing training sessions for health providers on oral cancer and tobacco intervention and cessation.

The Oral Cancer Medical Advisory Committee of the Maryland state Department of Health & Mental Hygiene has developed "Oral Cancer—Minimal Elements for Screening, Diagnosis, Treatment, Follow-up, and Care Coordination" to provide guidance for public health programs that screen for oral cancer.⁹⁴ As of January 2004, 5,156 individuals had received oral cancer examinations through local CRF programs, and over 2,097 had received educational services.

Another major outcome of the partnership was the passage of legislation and related funding to the DHMH Office of Oral Health for a statewide Oral Cancer Prevention Initiative. The Maryland Oral Cancer Prevention Initiative is based on a series of steps (Table 12.5) and is a continuation of the strong partnership between DHMH, NIDCR, the University of Maryland Dental School, and their many partners throughout Maryland. These steps are based on a state model developed by NIDCR to address oral cancer prevention and early detection.

Table 12.6
Maryland Oral Cancer Prevention Initiative

Statewide prevention and education public health approaches encompass:

- oral cancer education for the public, including the need to receive oral cancer examinations and information about risks, signs and symptoms, and smoking cessation.
- education/training of dental and non-dental health care providers to properly examine, diagnose, and refer patients.
- screening and referral, if needed, for biopsy and treatment targeting underserved, high-risk populations coordinated by local health departments.
- producing targeted health educational activities and materials that address tobacco use.
- developing a statewide public relations oral cancer prevention campaign that is similar to those that target other well-known cancers.
- local health department sponsorship of didactic training programs for health care providers throughout Maryland.
- conducting an evaluation of the program and assessing outcomes.

Source: DHMH, Office of Oral Health, 2000.

In 2000, the Maryland General Assembly rewarded the partnership's efforts when it passed legislation entitled "Oral Health Programs—Reducing Oral Cancer Mortality" (SB 791/HB1184) which requires the DHMH Office of Oral Health to prevent and detect oral cancer in the state, with a specific emphasis on targeting the needs of high-risk, underserved populations. Funding for this initiative was allocated in Fiscal Year 2002. Using the steps described in Table 12.5 as a basis for this program, many oral cancer prevention activities took place throughout the state, including the designation of "Oral Cancer Awareness Week" in Maryland every June. Highlights of this program, which won a Meritorious Award in Community Preventive Dentistry from the American Dental Association, are described in Table 12.6.

As part of this initiative, "Reduce Oral Cancer Mortality" grants were awarded to 21 of Maryland's 24 counties, the majority of whom provided oral cancer education for the public and health care providers including a training program for practitioners in conducting an appropriate oral cancer examination. The Eastern Shore counties developed an Oral Cancer Coalition to address prevention initiatives in the region, which included development of a two-year action plan and involvement of the Del Marva Shorebirds minor league baseball team in its public relation campaigns.

Other efforts from this initiative include the creation of a

public relations campaign via radio, television, print media, Baltimore Orioles and Ravens spokespersons, and Maryland Transportation Administration train posters; development of a toolkit to assist local jurisdictions in promoting and facilitating oral cancer prevention activities; and establishment of a Maryland Oral Cancer website (<http://www.maryland-oralcancer.org/>). Educational materials developed through the initiative consist of an "8 Steps of a Good Oral Cancer Exam" wallet card, "Having an Oral Cancer Exam" brochure for low-literacy populations, and Oral Cancer Awareness Week planning packets, lip balm, and prevention posters.

As a result of these efforts, thousands of Maryland residents have been screened for oral cancer and hundreds more have received oral cancer prevention messages and information. Others have been referred to smoking cessation programs. Finally, nearly 800 health care practitioners have received education and training regarding oral cancer prevention and examinations. Plans to evaluate the program to assess the needs of the public and health care providers are scheduled for the future.



Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁹⁵ related to oral cancer:

Objective:

Reduce the oropharyngeal cancer death rate to 2.7 deaths per 100,000 population.

The U.S. baseline was 3.0 per 100,000 in 1998 (age-adjusted to the 2000 U.S. standard population).

Objective:

Increase the proportion of oral and pharyngeal cancers detected at the earliest stage to 50%.

The U.S. baseline: 35% of oral and pharyngeal cancers (stage I, localized) were detected in 1990–1995.

Objective:

Increase the proportion of adults who, in the past 12 months, report having had an examination to detect oral and pharyngeal cancers to 20%.

The U.S. baseline: 13% of adults aged 40 years and older reported having had an oral and pharyngeal cancer examination in 1998 (age-adjusted to the 2000 U.S. standard population).

Oral Cancer Goals, Objectives, and Strategies

Goals:

Reduce oral cancer mortality.

Reduce disparities in the incidence and mortality of oral cancer.

Targets for Change

By 2008, reduce the oral cancer mortality to a rate of no more than 2.4 per 100,000 persons in Maryland.

The Maryland baseline was 3.0 per 100,000 in 2000 (age-adjusted to the 2000 U.S. standard population).

Source: Maryland Division of Health Statistics.

By 2008, increase the proportion of adults 40 and older who have had an oral cancer exam in the past year to 48%.

The Maryland baseline was 33.9% in 2002

Source: Maryland Cancer Survey.

**Objective 1:**

Increase oral cancer literacy among Marylanders.

Strategies:

1. Provide education to promote an understanding and awareness of oral cancer risk assessment and reduction, risk factors and behaviors, signs and symptoms, and the rudiments and frequency of adequate and timely oral cancer examinations to the public, health care providers, the media, and policy makers.
2. Provide specific educational messages to individuals with risk factors and to individuals who may choose to engage in high-risk behaviors in the future.
3. Use the media to provide culturally relevant and age-specific oral cancer literacy messages to the public at large. Consider public service announcements, paid advertisements, as well as various forms of media coverage including television, radio, and print.

Objective 2:

Increase provider education and training related to oral cancer prevention and early detection.

Strategies:

1. Require all currently practicing medical, nursing, and dental professionals to complete continuing education focused on oral cancer prevention and early detection (how to perform an oral cancer examination and tobacco cessation/intervention). This continuing education must be completed before the issuance of medical or dental licensure renewal.
2. Require all medical, nursing, and dental students to complete a cancer comprehension module that includes a test of proficiency in performing oral cancer examinations before receiving licensure.

3. Promote the inclusion of oral cancer prevention and examination training in all health care educational curricula.
4. Ensure that all health care providers adequately identify and assess patients with high-risk oral cancer behaviors.

Objective 3:

Increase public access to oral cancer prevention, early detection, and treatment services.

Strategies:

1. Provide an information clearinghouse for practitioners and patients regarding medical and/or dental coverage for smoking cessation, screening, testing, diagnosis, and treatment of oral cancer and related procedures.
2. Determine costs and payors for oral cancer treatments.
3. Develop a central state information resource for referral and case management of individuals with abnormal oral cancer examination results.
4. Provide uniform, functional dental coverage for adults within the Maryland Medicaid program that ensures an annual oral cancer examination and required follow-up care, if needed.
5. Provide case management and additional resources for uninsured and undocumented patients.
6. Promote coverage for all medically necessary dental procedures under private insurance plans, Medicare, and state Medicaid and managed care organizations.
7. Provide targeted education to individuals diagnosed with oral cancer or a pre-cancerous lesion regarding how to access services and the importance of decreasing risk behaviors.



8. Encourage private dental insurance companies, state Medicaid plans, and managed care organizations to honor coverage and adequate reimbursement of “Tobacco Counseling for the Control and Prevention of Oral Diseases.”
9. Revise the current forms needed for accessing the health care system into a format that is easily understood by the majority of the general public by taking into account low literacy and language barriers.
10. Develop a model for oral cancer patient navigators to assist patients in navigating the health care system upon diagnosis with oral cancer.

Objective 4:

Increase scientific knowledge regarding oral cancer.

Strategies:

1. Provide funding for research into all aspects of oral cancer prevention, early detection, and treatment.
2. Promote research in the following areas:
 - Practice patterns
 - Screening efficacy
 - HPV and other viral etiology as risk factors for oral cancer
 - Evaluation of existing programs
 - Stage of disease at diagnosis
 - Diagnosis patterns
 - Treatment and cures

Objective 5:

Maintain a centralized, statewide mechanism for support of oral cancer initiatives.

Strategies:

1. Maintain and increase funding for the Maryland State Oral Cancer Prevention Initiative and the DHMH Office of Oral Health.
2. Promote collaboration among Maryland’s professional schools to further oral cancer education and research.

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CHAPTER 13

CERVICAL CANCER

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CERVICAL CANCER

Cervical cancer incidence and mortality rates in the United States have been declining since the introduction of the Pap test, but cervical cancer rates worldwide remain high. Cervical cancer is the leading cause of cancer deaths among women in developing countries.

In 2000, nearly 500,000 cases of cervical cancer were diagnosed worldwide, second only to breast cancer for number of cancers diagnosed among women. About 230,000 deaths were caused by cervical cancer in 2000, making it the fifth leading cause of cancer deaths among women worldwide. About 80% of the new cases and deaths were in developing nations.¹

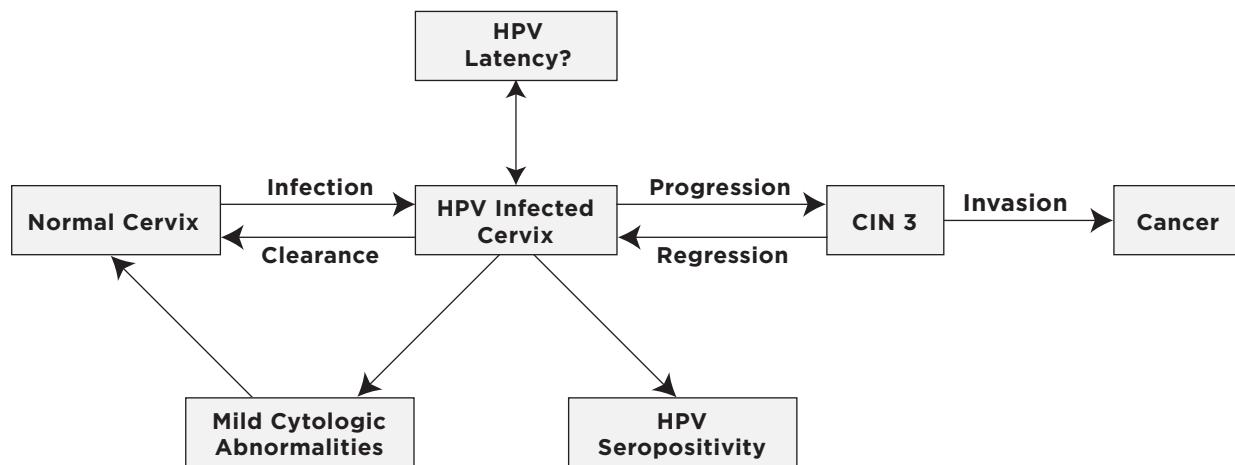
To a greater extent than with many cancers, effective tools for the control of cervical cancer have been identified. Since the development of the Pap test (Pap smear) in 1943, the number of women dying from cervical cancer in the United States has decreased by 75%.

Of the 50 million Pap tests done in the United States each year, approximately 7% will have an abnormal result. Although 85% of United States women report having a Pap test in the last three years, one half of the newly diagnosed cases of invasive cervical cancer occur in women who have never had one. An additional 10% of the cases occur in women who have not had a Pap test in the last five years. Certain strains of the human papilloma virus (HPV) of the cervix have been associated with an increased risk of developing invasive cervical cancer.^{2,3}

The lower part of the uterus is known as the cervix and it connects the uterus with the birth canal. Cervical cancer originates when cells on the surface of the cervix begin to grow uncontrollably. Initially the uncontrolled growth is not cancerous and may be referred to as cervical dysplasia, carcinoma in situ, or SIL (squamous intraepithelial lesions). If left untreated, the dysplasia may worsen and become carcinoma in situ. This is the earliest stage of cancer, when the tumor has not yet spread or invaded surrounding tissues. At this stage, dysplasia and carcinoma in situ can often be removed by a colposcopy-directed biopsy, or LEEP (loop electrosurgical excision).⁴

Invasive cancer develops when abnormal cells begin to invade normal cells. If the squamous epithelial cells in the lining of the ectocervix (outer part of the cervix) are invaded, a squamous cell carcinoma develops. Approximately 80% of all cervical cancers are squamous cell carcinoma. If the cells of the endocervix (inner part of the cervix) are affected, the cancer is called adenocarcinoma. If both the ectocervix and the endocervix are involved, the cancer is known as adenosquamous carcinoma. This occurs in 3%–5% of

Figure 13.1
Natural History of Cervical Cancer



Source: Mark Schiffman, MD, MPH, National Cancer Institute.

all cervical cancers. Other types of cervical cancer exist, but they are extremely rare.^{5,6,7}

Figure 13.1 describes the natural history of cervical cancer. Changes in the cells of the cervix form a continuum divided into low- or high-grade SIL or CIN 1, 2, and 3 that reflects increasingly abnormal changes of the affected epithelium. These lesions can persist, regress, or progress to an invasive malignancy. High-grade SIL (CIN 2–3) is more likely to persist or progress and less often regresses spontaneously, while low-grade SIL (CIN 1) often regresses without treatment. The average time for progression of CIN 3 to invasive cancer has been estimated to be 10–15 years, based on the mean age of diagnosis of these two conditions. There is a small subset of rapidly progressive cervical cancers that are diagnosed within three years of a confirmed negative Pap test. These tumors occur in younger women. One third of these cancers are adenocarcinomas of endocervical origin which may not be adequately screened by conventional Pap test methods.⁸

Risk Factors

Age

Rates of cervical carcinoma in situ (cervical cancer that has not spread to other parts of the body) reach a peak in both black and white women between the ages of 20 and 30 years. In contrast, rates of invasive cervical cancer increase with age in white women and black women, but rates increase more rapidly in black women. The

chance of dying from cervical cancer increases as women get older.⁹

Pap Test History

Women who have never had a Pap test or who have not had one for several years have a higher-than-average risk of developing cervical cancer.¹⁰

HPV Infection

There are over 80 types of human papillomavirus (HPV). At least two dozen types are transmitted sexually and can infect the cervix and about half of these have been linked to cervical cancer. Cervical infection with HPV is the primary risk factor for cervical cancer. However, HPV infection is very common and only a very small percentage of women infected with HPV will develop cervical cancer.¹¹

Human Immunodeficiency

Virus (HIV) Infection

Women who have been infected with HIV have a higher-than-average risk of developing cervical cancer.¹²

Sexual History

Women who had sexual intercourse at an early age or who have had many sexual partners have a higher-than-average risk of developing cervical cancer.¹³

Smoking

Cigarette smoking by women is associated with an increased risk for squamous cell carcinoma.¹⁴

Table 13.1
Cervical Cancer Incidence and Mortality Rates by Race
in Maryland and the United States, 1999

Incidence 1999	Total	Whites	Blacks
New Cases (#)	226	130	73
Incidence Rate	8.2	6.7	10.8
U.S. SEER Rate	8.0	7.4	13.3
Mortality 1999	Total	Whites	Blacks
MD Deaths (#)	77	49	26
MD Mortality Rate	2.8	2.4	4.2
U.S. Mortality Rate	2.9	2.6	5.5

Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1999; Maryland Division of Health Statistics, 1999; SEER, National Cancer Institute, 1999.

Burden of Cervical Cancer in Maryland

Invasive cervical cancer represents about 2% of all newly diagnosed cancers among Maryland women. In 1999, 226 Maryland women were diagnosed with invasive cervical cancer (Table 13.1). The overall age-adjusted incidence rate for invasive cervical cancer in Maryland for 1999 was 8.2 per 100,000, similar to the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) national estimates of 8.0 per 100,000. Cervical cancer incidence rates are higher among black women than white women in Maryland and the U.S.

Age-specific invasive cervical cancer incidence rates for black women are higher than those for white women starting at age 40 (Figure 13.2). Cervical cancer incidence rates decreased an average of 6% per year from 1995 to 1999 in Maryland,¹⁵ however the decline in the incidence rate among white women is greater than the decline among black women (Figure 13.3). White women are diagnosed at the local stage more frequently than black women (55% vs. 45%) in Maryland, while a large proportion of black women are diagnosed at regional and distant stages (Figure 13.4).

Currently, the Maryland Cancer Registry does not calculate survival rates, but SEER data show that the overall five-year survival rate for invasive cervical cancer is 72% for white women and 60% for black women. Black women have lower five-year survival rates than

white women at each stage (Table 13.2).¹⁶

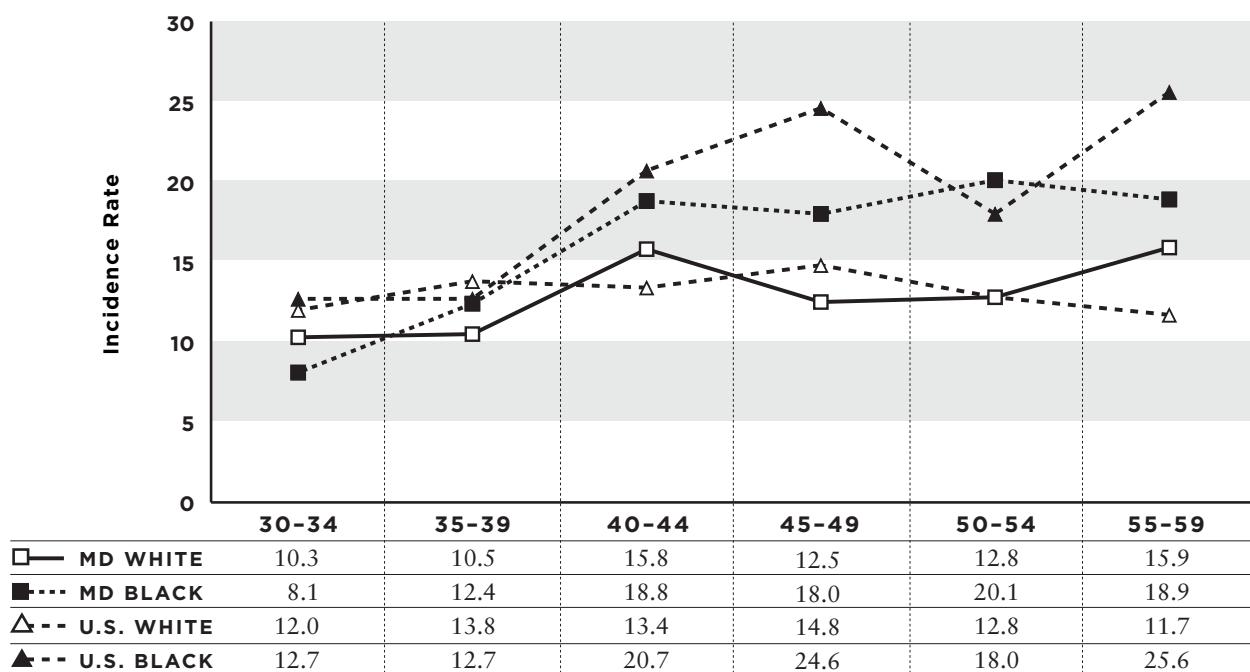
In 1999, 77 Marylanders died from invasive cervical cancer (Table 13.1). The age-adjusted invasive cervical cancer mortality rate in Maryland was 2.8 per 100,000, which is similar to the U.S. rate of 2.9 per 100,000 in 1999. Mortality rates among white women in Maryland and the United States have remained fairly constant from 1995 through 1999, but rates among black women have declined sharply since 1997 (Figure 13.5). Although mortality rates for black women are still significantly higher than rates for white women, the recent decline may indicate that this gap is closing and a health disparity is being reduced.

Baltimore City and the Eastern Shore have significantly higher cervical cancer mortality rates than the U.S. Montgomery County and the Baltimore Metropolitan areas (excluding Baltimore City) have statistically significantly lower mortality rates than the United States (Figure 13.6).

Disparities

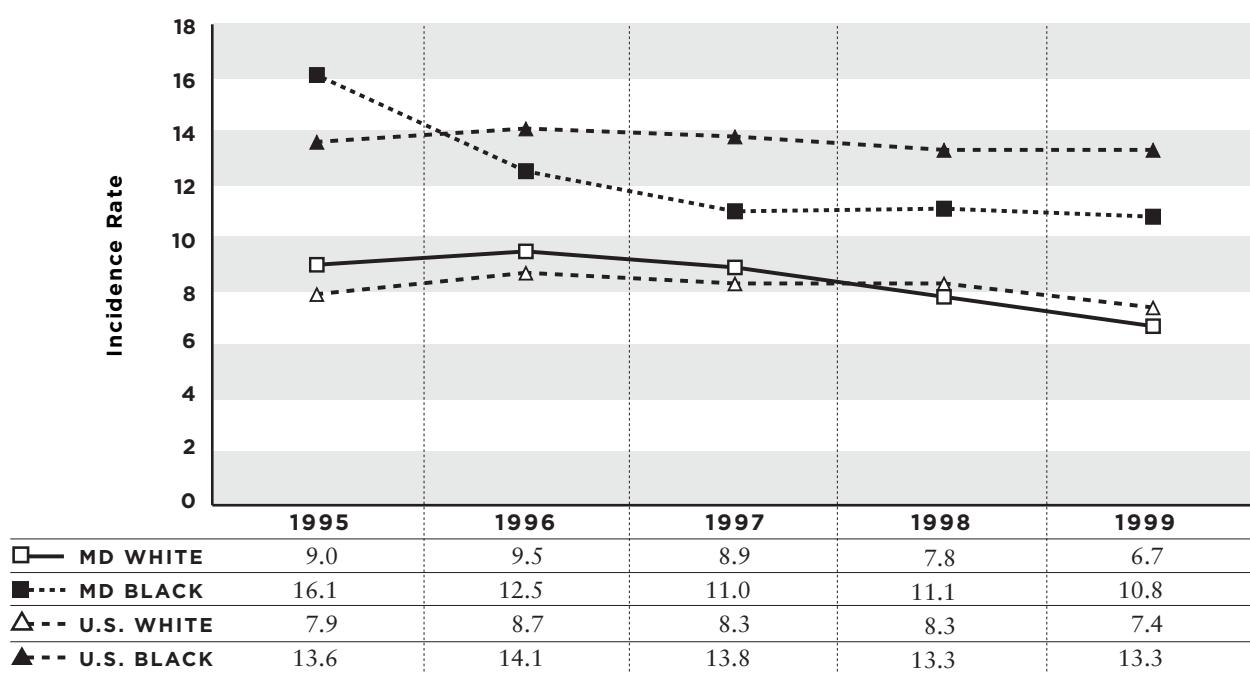
- Black women have a significantly higher incidence rate and mortality rate for invasive cervical cancer than white women.
- For each stage, black women have lower five-year survival rates than white women.

Figure 13.2
Invasive Cervical Cancer Age-Specific Incidence by Race
in Maryland and the United States, 1995-1999



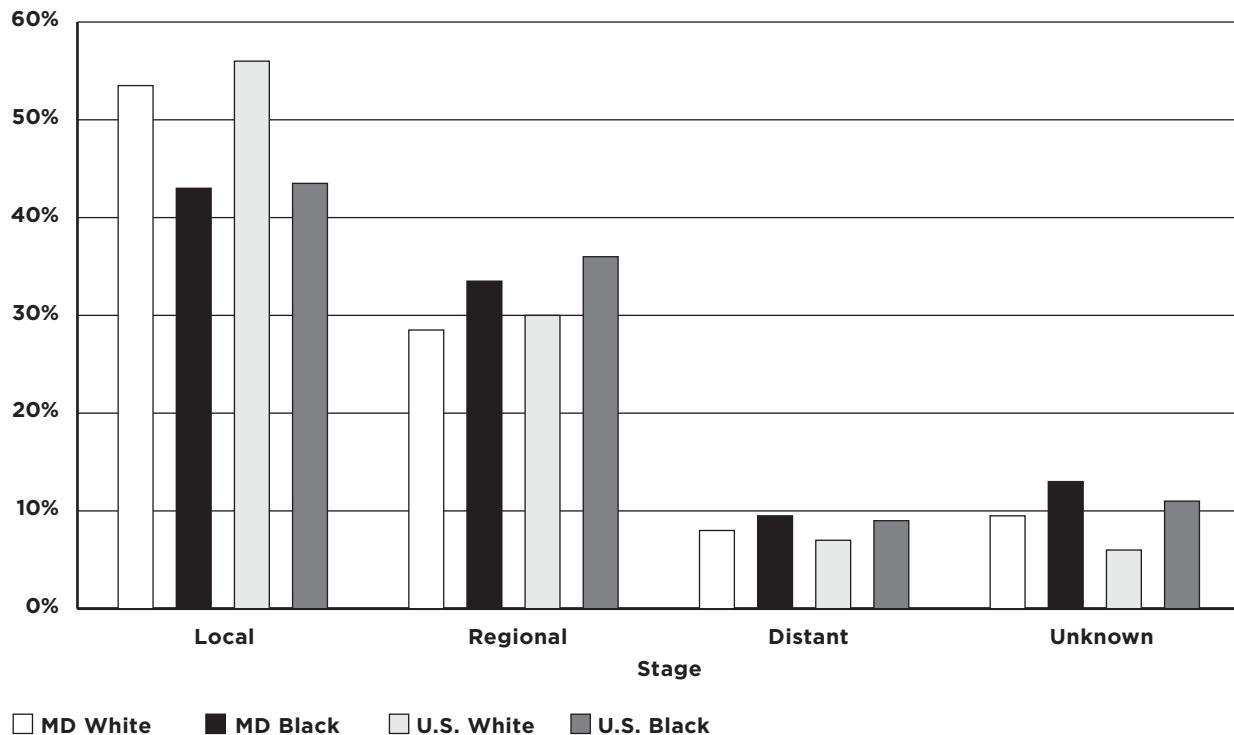
Rates are per 100,000 population.
Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 13.3
Invasive Cervical Cancer Incidence by Race
in Maryland and the United States, 1995-1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Cancer Registry, 1995-1999; SEER, National Cancer Institute, 1995-1999.

Figure 13.4
Invasive Cervical Cancer Stage of Disease at Diagnosis
by Race in Maryland and the United States, 1992–1997



Source: Maryland Cancer Registry, 1992–1997; SEER, National Cancer Institute, 1992–1997.

Cervical Cancer Among Other Ethnic and Cultural Groups in Maryland

Historically reliable data have only been available on cancer rates for whites and blacks. The numbers of cancer cases and deaths among other minority groups have been small, making rates unreliable for comparisons. With demographics in Maryland constantly shifting, including growing numbers of other ethnic minorities (due to both immigration and birth), it will be more and more important to have accurate data on all ethnic groups. Recent improvements in national and state standards for accurately recording information and vital statistics data about all ethnic groups in cancer data will improve our ability to monitor the health of these groups.

During the last decade, a large influx of immigrants has settled in Maryland. According to the 2000 Census, the number of Hispanics in Maryland has increased by 6.5 times and the number of Asians in Maryland has increased by 5.5 times since the 1990 Census. Nearly half of the total number of Hispanics and Asians in the

Maryland are living in Montgomery County, where they comprise about 22% of that county's total population. Some of these immigrants are from Central America and Southeast Asia, areas that have very high cervical cancer incidence and mortality rates. Central America has cervical cancer incidence and mortality rates about 5 times the U.S. rates; Southeast Asia about 2.5 times the U.S. rates. If the women in these groups are unable or unwilling to receive screening, diagnosis, and treatment, there may be an epidemic of cervical cancer in Maryland, centered in Montgomery County. The potential for a significant disparity and a public health problem for cervical cancer may exist in Maryland and should be considered despite the lack of data at the moment.

Primary Prevention

Avoiding risk for HPV infection is the most important strategy for primary prevention of cervical cancer. Epidemiologically, women who have first sexual intercourse at an early age and those who have multiple sexual partners have been shown to be at increased risk

Table 13.2
Cervical Cancer Five-Year Survival Rates by Race in the United States, 1992-1999

Stage	Total	White	Black
Overall	71%	73%	61%
Local	92%	93%	87%
Distant	17%	18%	12%

Source: SEER, National Cancer Institute, 1992-1999.

for infection. In addition, barrier methods of contraception, and possibly spermicides,¹⁷ may prevent the spread of HPV between partners.

In addition to HPV infection, other factors may reduce or increase the risk for the development of cervical cancer. For example, tobacco exposure and HIV infection increase risk for cervical cancer and dietary factors may have a preventive effect. Several case-control studies have investigated the effects of various micronutrients on risk and have found that high dietary carotene and possibly vitamins C and E and folate are associated with reduced risk for cervical cancer.¹⁸ Education regarding risk factors for cervical cancer may lead to behavioral modification resulting in diminished exposure.

Screening and Evidence of Benefit

Early detection, using cervical cytology, is currently the only practical means of detecting cervical cancer in localized or premalignant stages.¹⁹ The widespread use of the Pap test in the U.S. makes the possibility of testing the efficacy of cervical cytology by randomized trials remote. There is, nevertheless, substantial evidence from observational studies that screening can reduce mortality from cervical cancer. Cervical cancer mortality rates have decreased in several large populations following the introduction of well-run screening programs. Data from several large Scandinavian studies show sharp reductions in incidence and mortality following the initiation of organized screening programs. Iceland reduced mortality rates by 80% over 20 years, and Finland and Sweden reduced their mortality by 50% and 34%, respectively. Similar reductions have been found in large populations in the United States and Canada.²⁰

Reductions in incidence and mortality seem to be proportional to the intensity of screening efforts as evi-

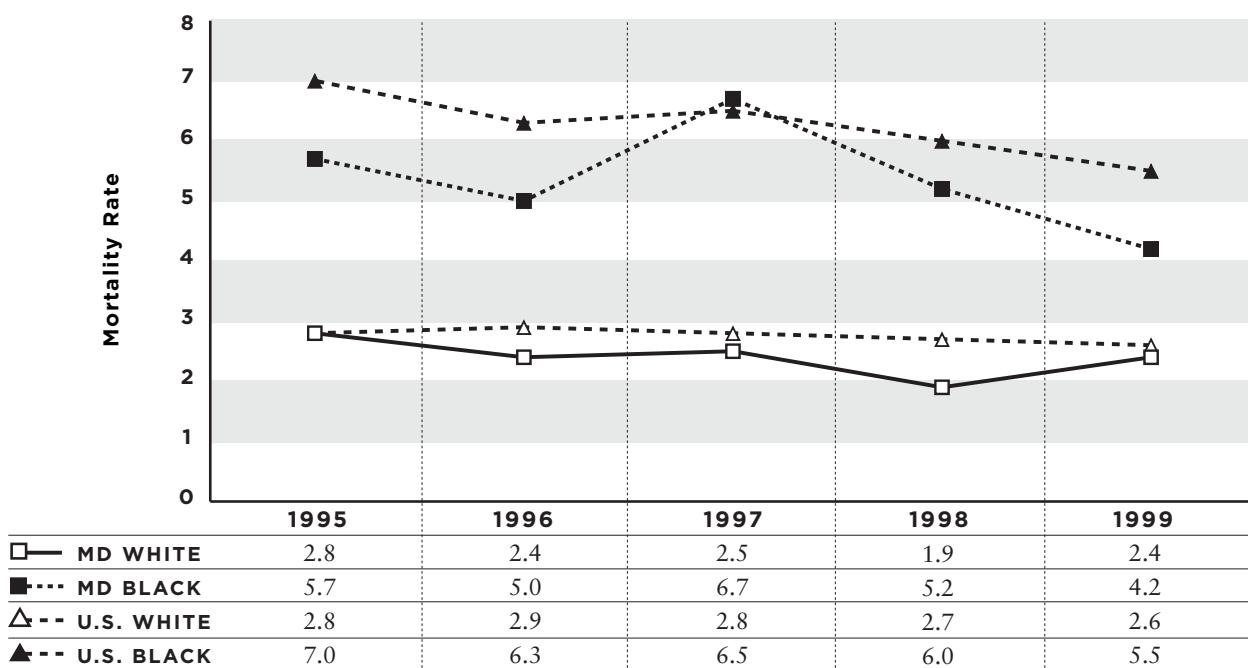
denced by the Scandinavian countries with the highest rates of screening activity reporting greater reductions in mortality than those countries with lower rates of screening. Mortality in Canada was reduced most remarkably in British Columbia, which had screening rates of 2 to 5 times those of the other provinces. Case-control studies have found that the risk of developing invasive cervical cancer is 3 to 10 times greater in women who have not been screened. Risk also increases with longer duration following the last normal Pap test, or similarly, with decreasing frequency of screening. Screening every two to three years, however, has not been found to increase significantly the risk of finding invasive cervical cancer above the risk expected with annual screening.²¹

Although vaginal smears are often done for follow-up of women who have had a hysterectomy for malignancy, a retrospective study suggests little or no benefit of routine vaginal screening for women who have had a hysterectomy for benign conditions. Investigators found a low prevalence of vaginal dysplasia (0.1%) and a high false-positive rate for vaginal smears from women who have had a hysterectomy for benign disease.²²

Targeting High-Risk Patients

In order to reduce cervical cancer mortality, the percentage of cervical neoplasms discovered in the precancerous or localized stages must increase. This can be accomplished most effectively by screening women at greatest risk for developing cervical cancer (i.e. those who have not had a Pap test or those who have not had one for several years). Often, these women are older, of lower socioeconomic status, may be members of minority groups, and are often seen by physicians for a variety of acute and chronic conditions unrelated to preventive medical care. Women infected with the human immunodeficiency virus (HIV) represent another important

Figure 13.5
Invasive Cervical Cancer Mortality Rates by Race
in Maryland and the United States, 1995–1999



Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population.
Source: Maryland Division of Health Statistics, 1995–1999; SEER, National Cancer Institute, 1995–1999.

group at increased risk for development of cervical cancer. They have been shown to have a 2.28-fold increased risk of invasive cervical cancer compared to women without HIV. HIV-seropositive women also show an increased frequency of abnormal Pap test results (12.5 times higher than seronegative women) and a concomitant increase in cervical and anal human papillomavirus.²³

After the age of 25, the incidence of invasive cancer in black women increases rapidly with age, while in white women the incidence rises more slowly. Mortality also increases with advancing age, with dramatic differences between black and white women. Thus, extra effort is warranted to reach older women who have not been screened or who are not screened on a regular basis. Over 25% of the total number of invasive cervical cancers occur in women older than 65, and 40% to 50% of all women who die from cervical cancer are over 65 years of age. A large proportion of women, particularly elderly black women and middle-aged poor women, have not had regular Pap tests in their lifetimes. These patterns underscore the importance of special screening efforts targeted to reach women who do not receive regular screening.²⁴

Screening Guidelines

The recommendations for the initiation of cervical cancer screenings and the interval between cervical cancer screenings have changed recently. Guidelines from the American Cancer Society, the U.S. Preventive Services Task Force, and the National Cancer Institute are very similar.

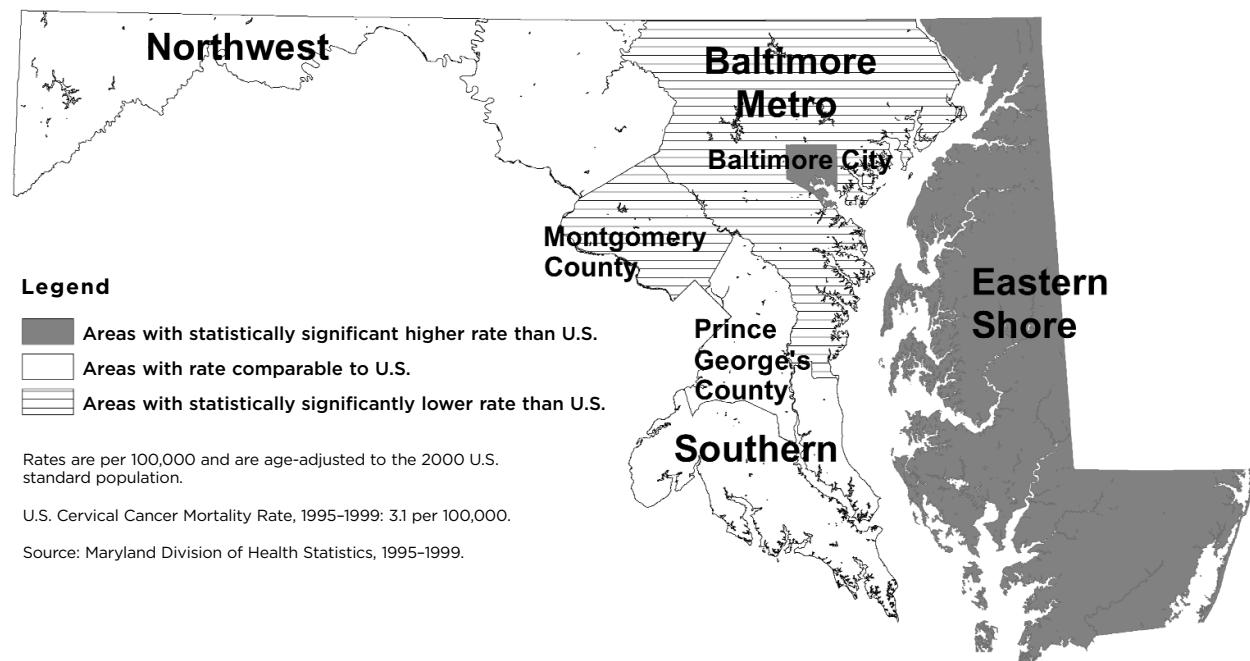
The American Cancer Society recommends beginning cervical cancer screening three years after first vaginal intercourse and no later than age 21. The ACS also recommends that women age 30 and older who have had three consecutive negative Pap tests can be screened every two to three years.²⁵

The National Cancer Institute's summary points for cervical cancer screening are:²⁶

- Cervical cancer screening should begin approximately three years after a woman begins having sexual intercourse, but no later than 21 years old.
- Experts recommend waiting approximately three years following the initiation of sexual activity because transient HPV infections and cervical cell changes that are not significant are common

Figure 13.6

**Maryland Cervical Cancer Mortality Rates by Geographical Area:
A Comparison to Rates in the United States, 1995-1999**



and it takes years for a significant abnormality or cancer to develop. Cervical cancer is extremely rare in women under the age of 25.

- Women should have a Pap test at least once every three years.
- Women 65 to 70 years of age who have had at least three normal Pap tests and no abnormal Pap tests in the last 10 years may decide, upon consultation with their health care provider, to stop cervical cancer screening.
- Women who have had a total hysterectomy (removal of the uterus and the cervix) do not need to undergo cervical cancer screening unless the surgery was done as a treatment for pre-cancerous cervical lesions or cervical cancer.
- Women should seek medical advice about when they should begin screening, how often they should be screened, and when they can discontinue cervical screenings, especially if they are at higher than average risk of cervical cancer due to factors such as HIV infection.

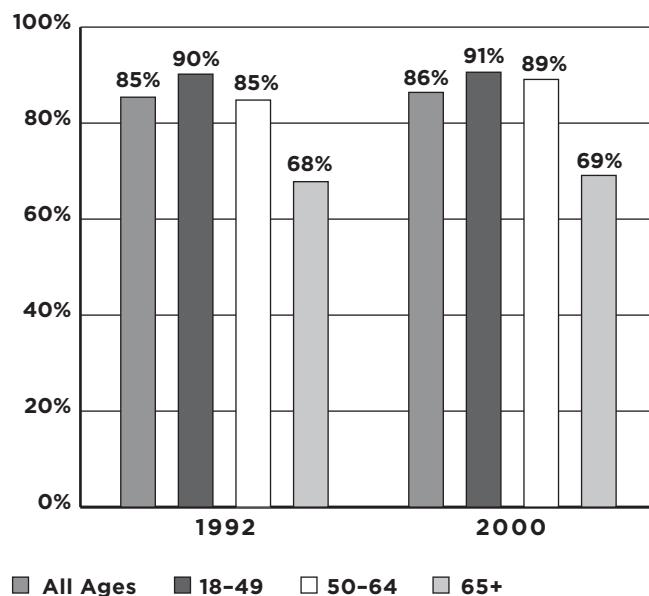
The U.S. Preventive Services Task Force (USPSTF)

strongly recommends screening for cervical cancer in women who have been sexually active and still have a cervix. Indirect evidence suggests most of the benefit can be obtained by beginning screening within three years of onset of sexual activity or age 21 (whichever comes first) and screening at least every three years. The USPSTF recommends against routinely screening women older than age 65 for cervical cancer if they have had adequate recent screening with normal Pap tests and are not otherwise at high risk for cervical cancer. The USPSTF recommends against routine Pap test screening in women who have had a total hysterectomy for benign disease.²⁷

Use of New Cervical Cancer Screening Technologies

The USPSTF concludes that the evidence is insufficient to recommend for or against the routine use of new technologies such as liquid-based cytology, computerized rescreening, and algorithm-based screening to screen for cervical cancer. The USPSTF found poor evidence to determine whether these new technologies are more effective than conventional Pap test screening in reducing the incidence of, or mortality from, invasive cervical

Figure 13.7
Percent of Women Reporting a Pap Test in the Past Three Years by Age in Maryland, 1992 and 2000



Source: BRFSS, 1992 and 2000.

cancer. Evidence to determine both sensitivity and specificity of new screening technologies is limited. As a result, the USPSTF concluded that it cannot determine whether the potential benefits of new screening devices relative to conventional Pap tests are sufficient to justify a possible increase in potential harms or costs.²⁸

The USPSTF concludes that the evidence is insufficient to recommend for or against the routine use of human papillomavirus (HPV) testing as a primary screening test for cervical cancer. The USPSTF found poor evidence to determine the benefits and potential harms of HPV screening as an adjunct or alternative to regular Pap test screening. The use of HPV testing for primary population-based screening is not recommended due to low specificity, particularly among young sexually active women.²⁹ Trials are underway that should soon clarify the role of HPV testing in cervical cancer screening.³⁰

The best use of HPV testing may be as a secondary test following an abnormal Pap test result (ASC-US), allowing the focus of work-up and treatment of those women who are most likely to progress to advanced disease. The American Society for Colposcopy and Cervical Pathology recommends that an HPV high-risk panel test be performed after a Pap test with the result of ASCUS. HPV testing could also be used post-treatment where a positive test may indicate residual disease.^{31,32,33,34,35}

HPV infection is well established as a necessary but not a sufficient condition for development of cervical cancer.^{36,37,38} Only a few types of HPV are associated with the majority of cervical cancer.³⁹ Eventually it may be possible to vaccinate against HPV infection.⁴⁰

Screening Rates

Data from the Behavioral Risk Factor Surveillance System (BRFSS) show that the proportion of Maryland women 18 years and older who report having a Pap test in the past three years has increased slightly from 84% in 1992 to 87% in 2000.⁴¹ Maryland's Pap test screening rates are slightly higher than those for the United States. Pap test screening rates for white and black women are similar but screening rates for women 65 years of age and older are much lower than those for younger women (Figure 13.7).⁴² The lower screening rates among older women are of concern given that the incidence of cervical cancer is higher in these women.

Screening Behavior, Beliefs, and Barriers

In 1997 and 1998, six focus groups were conducted of Maryland women, ages 50 to 75, who had not had a

regular Pap test in the past year and had not had more than two Pap tests in the past five years. The following were key findings:⁴³

- Most women only go to the doctor when something is wrong and do not go on a regular basis.
- Participants were concerned with many health problems but none mentioned cervical cancer among their top health concerns.
- Few women knew why they should have a Pap test or anything about cervical cancer.
- Barriers to getting Pap tests included: embarrassment, discomfort, fear, test inaccuracy, cost, lack of perceived need, inconvenience, motivation, insurance issues, absence of a doctor's recommendation, and general negative feelings about doctors.
- Participants said they would be motivated by the following to get regular Pap tests: being reminded to do so, convenience, low cost, less embarrassment, knowing someone who had cancer, and increased public awareness.
- Participants suggested the following to make women more aware of the importance of getting regular Pap tests: television, newspapers, magazines, radio, posters, health fairs, billboards, videos, and materials from their insurer.

Screening in the Hospital Setting

In 1977, the Maryland legislature passed Senate Bill 59, which requires hospitals to offer a Pap test to all female inpatients. The law does not provide any funds for implementation and enforcement. A survey by Johns Hopkins University in 1986 indicated that 25% of women who had been hospitalized there reported never having a Pap test.⁴⁴ Another survey by Johns Hopkins University in 1995 indicated that hospitals do not object to offering Pap tests to patients and suggested that an education component and linkages to referrals should be provided to patients. In the past, some hospitals employed nurses whose job was to visit female inpatients and offer them Pap tests. This seems to have been successful.⁴⁵

Physician Practices and Barriers

Physicians play an important role in recommending and providing cancer screening. A study in North

Carolina showed that obstetrician/gynecologists recommend annual Pap test screening more frequently than physicians in other specialties.⁴⁶

Compliance with screening recommendations was greater among those women who received a reminder letter for a Pap test and mammogram.⁴⁷ A physician reminder letter combined with telephone counseling from a health educator significantly increased women's use of both mammograms and Pap tests in a low-income population in a managed care setting.⁴⁸ However it is worth noting that implementation of an office chart reminder system and use of patient health maintenance cards to improve cancer screening was feasible for the Pap test and clinical breast exam, but not for mammography.⁴⁹

In addition, male physicians reported that patients requested a referral to a female physician to perform Pap tests and CBE more often than any other tests. Male physicians perceived patients' embarrassment as a stronger barrier to performing Pap tests and CBE than female physicians.⁵⁰

Ideal Model for Cervical Cancer Control

There are five steps in the ideal cervical cancer control process, depicted in Figure 13.8. The process begins with a woman who is aware of the recommended screening guidelines, has access and availability to screening, diagnosis and treatment, and, if she is a survivor, has discussed survivorship issues (e.g., childbearing, fertility). Every woman should have a primary care provider who either performs an adequate Pap test or refers her to another provider to perform the Pap test. Next, the provider, who has kept abreast of current clinical guidelines, follows up with the woman regarding her test results. Then, the Pap test is sent to a lab in compliance with the Clinical Laboratory Improvement Act (CLIA) and is read by a cytotechnologist or cytopathologist who reports the results using the Bethesda System. If a diagnosis is required, various diagnostic procedures are carried out by a trained colposcopist, and treatment is performed by a gynecologist or other trained specialist to remove precancerous or cancerous lesions of the cervix.

The following barriers to the ideal cervical cancer control process were identified by the Cervical Cancer Committee:

- The Maryland Breast and Cervical Cancer

Figure 13.8
Ideal Model for Cervical Cancer Control

Women in Need	Long-Term Preventive Care by Primary Care Provider
Are aware of recommended screening guidelines for age, risk factors, sexual activity, and previous Pap test results.	Takes adequate history and performs adequate Pap test or refers to a provider who takes a history and performs a Pap test.
Have access and availability to screening, diagnosis, and treatment.	Prepares adequate Pap test. Collects sample for HPV test (when appropriate).
Have survivorship issues addressed for survivors (e.g., childbearing, fertility, and psychosocial issues).	Receives cytology report and communicates with lab. Understands cytologist's report. Notifies woman of Pap result regardless of outcome.
	Repeats Pap test if "unsatisfactory." Recommends repeat Pap at a specified interval. Keeps abreast of clinical guidelines related to cervical cancer. Makes appointment for subsequent Pap tests and other follow-up. Is aware of low-cost or free programs for screening, diagnosis, or treatment and makes referrals to programs for the financially needy.

Program has enough funds to screen 10%–15% of uninsured women aged 40–64 in the state for cervical cancer. This leaves significant numbers of women who are uninsured or underinsured who cannot afford cervical cancer screening.

- Accessibility to screening services may be limited because of hours of operation, availability of public transportation, or lack of knowledge among patients and providers about the availability of existing services, especially for the socioeconomically disadvantaged.
- Cultural and language barriers prevent women from seeking screening and treatment. Few hospitals and even fewer physicians have staff who are able to speak to patients in their native languages and must resort to using family members or friends of the patient as translators.
- Written information available to patients is often only provided in English and Spanish and is rarely

written at a reading level that is easy for all patients to understand.

- An increasing number of providers refuse Medicare or Medicaid patients because of limited reimbursements.
- Funds available in the Breast and Cervical Cancer Diagnosis and Treatment Program are insufficient to serve all uninsured or underinsured women diagnosed with cervical cancer in Maryland.
- There is a need to educate physicians (particularly primary care providers) regarding screening and follow-up guidelines and new technologies for performing Pap tests.
- Studies have shown that many older women do not go for cervical cancer screenings because their physicians fail to recommend that they go and the women underestimate their risk of getting cervical cancer. Many older women never see a gynecolo-

Cytology Interpretation by Laboratory	Diagnosis by Trained Colposcopist	Treatment by Gynecologist and/or Other Specialist
Has passed Maryland Cytology Proficiency Testing and is in compliance with CLIA.	Carries out diagnostic procedures, which might include repeat Pap tests, colposcopy, and biopsy.	Removes pre-cancerous lesion with most appropriate state-of the-art treatment.
Reads Pap test with high degree of sensitivity and specificity.	Sends biopsy specimen to pathologist.	Provides follow-up care as needed.
Reports results to the provider using the current Bethesda System.	Receives pathologist's report.	Keeps abreast of clinical guidelines related to cervical cancer.
Performs HPV test on all ASC-US Pap tests.	Keeps abreast of clinical guidelines related to cervical cancer.	
Educes provider on Bethesda System and management of abnormalities, documents communication with primary care provider.		
Keeps abreast of clinical guidelines related to cervical cancer.		

Source: Developed by the Cervical Cancer Committee of the Maryland Comprehensive Cancer Control Plan.

gist and their primary care provider may not perform a Pap test.^{51,52}

- There are some counties in Maryland where residents must wait four months to have a colposcopy because there are a limited number of providers in Maryland who are trained as colposcopists.
- Many women who lack insurance and the financial means to pay for their care may go without diagnostic tests and treatment.

the provision of breast and cervical cancer outreach, patient and public education, screening, referral, follow-up, and case management services for its residents. The DHMH formed a Cervical Cancer Medical Advisory Committee, which developed guidelines, "Minimal Clinical Elements for Cervical Cancer Screening." This document provides guidance for public health programs that screen for cervical cancer.

Since 1992, the BCCP has provided 29,244 initial Pap tests and 32,164 subsequent Pap tests. Thirty percent of the women screened in the BCCP indicated that they were never or rarely screened (not in the past five years) for cervical cancer. In 2001, BCCP provided services for approximately 10% of eligible women in the state.

Current Efforts in Maryland

The Maryland Department of Health and Mental Hygiene (DHMH) Breast and Cervical Cancer Program (BCCP) is a statewide program that provides breast and cervical cancer screening services to uninsured or underinsured low income (less than 250% of the federal poverty level) women 40–64 years of age. Across the state, the DHMH awards funds to each jurisdiction to coordinate

In addition to the BCCP, funding from the Cigarette Restitution Fund has been awarded to the University of Maryland Medical System/University Care to provide breast and cervical cancer screening for low income

uninsured or underinsured women who live in Baltimore City. Several other Maryland jurisdictions also offer cervical cancer education and screening services under this program. As of January 2004, 1212 women had been screened for cervical cancer through these local programs and over 8,608 had received breast and cervical cancer educational services.

There are several other programs in Maryland that provide testing, diagnostic, treatment, and support services for women. The Maryland Family Planning Program is funded by federal Title X Family Planning funds and state funds. With over 90 family planning sites in Maryland, the mission of this program is to decrease the incidence of unintended pregnancies and improve pregnancy outcomes. Grants are given to all local health departments and two Planned Parenthood affiliates. The program offers all forms of birth control, treatment for minor gynecological problems, sexually transmitted infection screening, annual Pap tests and colposcopy services. The program serves approximately 70,000 patients each year, including 2,000–3,000 men. It is open to women of reproductive age and will accept undocumented aliens and teenagers as patients. Services are provided under a sliding fee scale and there is no charge for teenagers or other individuals whose income levels are below designated points on the sliding fee scale. The program also accepts women with Medical Assistance and insurance. However, the target population is teens and uninsured/underinsured low-income women.

The Maryland Breast and Cervical Cancer Diagnosis and Treatment Program is state-funded and reimburses participating medical providers for breast and cervical cancer diagnostic and treatment services for Maryland residents who are diagnosed with either breast or cervical cancer, meet income guidelines (250% of the poverty level), and are either uninsured or underinsured for these services. This program is not restricted by age.

The Women's Breast and Cervical Cancer Health Program provides Medicaid coverage to women screened under the BCCP who have been diagnosed with either breast or cervical cancer. Women in this program are eligible for full Medical Assistance while they are undergoing treatment for breast or cervical cancer.

The American Cancer Society (ACS) provides educational and support services for cervical cancer patients, including several support groups. Assistance with transportation for cancer treatments can be obtained in some

areas of the state through the Road to Recovery program. The ACS publishes numerous educational brochures, and can send speakers to community meetings.

Healthy People 2010 Objectives

The following are the Healthy People 2010 objectives⁵³ related to cervical cancer:

Objective:

Reduce the invasive cervical cancer death rate to 2.0 per 100,000.

The U.S. baseline was 3.0 per 100,000 in 1998 (age-adjusted to the 2000 standard US population).

Objective:

Increase the proportion of women aged 18 and older who have ever received a Pap test to 97%.

The U.S. baseline was 92% in 1998 (age-adjusted to the year 2000 standard population; includes women without a uterine cervix).

Objective:

Increase the proportion of women aged 18 and older who have received a Pap test within the previous three years to 92%.

The U.S. baseline was 79% in 1998 (age-adjusted to the year 2000 standard population; includes women without a uterine cervix).



Cervical Cancer Goals, Objectives, and Strategies

Goal:

Reduce cervical cancer mortality in Maryland.

Targets for Change

By 2008, reduce cervical cancer mortality to a rate of no more than 1.9 per 100,000 persons in Maryland.

The MD baseline was 2.3 per 100,000 in 2000 (age-adjusted to the 2000 U.S standard population).

Source: Maryland Division of Health Statistics.

By 2008, increase the number of women aged 18 and older who have had a Pap test in the past three years to 94%.

The MD baseline was 90% in 2000.

Source: BRFSS.

Objective 1:

Increase awareness in the general public of cervical cancer screening recommendations and availability of programs.

Strategies:

1. Increase educational activities among all population groups as to the importance of regular screening.
2. Increase awareness of the availability of screening programs to the general public.
3. Develop culturally sensitive educational messages.
4. Partner with smoking cessation programs.
5. Focus educational and outreach programs on high-risk populations (e.g., recent immigrants, African-American women, HIV-positive women).

Objective 2:

Increase cervical cancer screening in women who have not been screened in the last five years, especially older women, and increase compliance with recommended follow-up.

Strategies:

1. Identify characteristics of women who may not have been screened in the past five years (e.g., examine changing demographics of the state population).
2. Increase outreach efforts to reach the underserved.
3. Provide low cost/easily accessible mechanisms for the screening of low-income individuals.
4. Encourage providers to have an organized mechanism to track patients, particularly those with high-grade lesions that fail to follow-up.
5. Focus screening and follow-up programs on high-risk populations (e.g., recent immigrants, HIV-positive women).



6. Encourage primary care providers to offer Pap tests or refer patients to providers who offer Pap tests, and then systematically track compliance to assure that their patients receive a Pap test.
7. Continue federal and state funding for the breast and cervical cancer early detection and treatment program.
8. Increase awareness of the availability of screening programs to providers.
9. Provide Pap tests to women seen in hospital inpatient or outpatient settings, including emergency rooms, and assure that a mechanism for follow-up is available.
10. Amend SB 59, Section 19–348 to “provide” Pap tests to all inpatients. Examine hospitals that succeed at providing Pap tests to inpatients. Share lessons learned at these locations with other hospitals.
11. Link Pap test performance or referral to physician re-certification from the Board of Physician Quality Assurance. Monitor providers by adding Pap testing as a HEDIS measure (Health Insurance Employee Data and Information Set).
12. Explore the feasibility of using a colposcopy van to provide colposcopy services to rural and underserved areas of the state.

Objective 3:

Ensure that all providers have access to state-of-the-art guidelines for the management of cervical abnormalities.

Strategies:

1. Disseminate management guidelines (ASCCP) to practitioners who care for women with cervical abnormalities.

Objective 4:

Ensure access to medical care for all.

Strategies:

1. Increase funding for health care centers that serve indigent women and include funding for staff to provide follow-up services.
2. Provide funding so that all women can obtain a Pap test and follow-up procedures regardless of insurance status.
3. Ensure access to prevention, screening, treatment, and follow-up care for all Maryland residents.

Objective 5:

Conduct Maryland-specific surveillance research on barriers to cervical cancer detection and treatment by establishing a statewide follow-back study mechanism to allow for monitoring of failures through follow-back and to evaluate and modify intervention strategies.

**Objective 6:**

Determine why there are discrepancies in survival among different segments of the state population, taking into account multiple factors including race and age.

Strategies:

1. Conduct a follow-back study to determine the factors that contribute to women developing and/or dying from invasive cervical cancer. Identify factors that influence or hinder health-seeking behaviors (e.g., screening, diagnosis, treatment) for the patient. Also identify factors within the health care system that influence screening, diagnosis, and treatment.
2. Establish and maintain mechanisms to monitor the proportion of cervical cancer cases and deaths attributable to failures of detection, and the proportion attributable to failures of treatment. Identify strategies and implement activities to minimize failures of detection and failures of treatment.
3. Explore whether alternative screening techniques should be used for special populations.
4. Encourage research to determine why discrepancies in survival exist and what factors can be changed to erase such discrepancies.

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CHAPTER 14

PAIN MANAGEMENT



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PAIN MANAGEMENT

Cancer pain can effectively be treated in 85% to 95% of patients using an integrated pain management program consisting of therapies such as medication, nerve blocks, cognitive-behavioral therapy, radiation therapy, and surgery.¹ However, many cancer patients suffer from unrelieved pain from diagnosis throughout their disease trajectory.² The World Health Organization estimates that up to 70% of patients with cancer pain do not receive adequate relief.³ Cancer pain is present in 24% to 62% of adult patients at the time of diagnosis,^{4,5} in 35% to 57% of patients receiving active treatment,^{6,7} and in 88% to 100% of patients in the terminal phase of disease.⁸ Similar statistics are found in children.^{9,10,11} Cancer is the second leading cause of death in Maryland, accounting for 24% of all deaths, and currently Maryland

ranks eleventh in the nation for overall cancer mortality.¹² Over 23,000 cases of cancer were diagnosed in Maryland in 1999;¹³ the fact that a large number of these patients will experience unrelieved pain constitutes a public health crisis. Additionally, as the population ages and people over the age of 65 become our fastest growing demographic group, cancer pain issues will become even more prevalent.¹⁴

Cancer pain affects not only pain sufferers, but also their partners, family, and friends. Cancer pain is a family issue. Cancer pain affects the relationships patients have with their significant others and impacts their daily activities, life goals, and quality of life.^{15,16}

In a recent *Last Acts* report on pain at the end of life, Maryland earned a grade of B in regard to its state pain policies that allow physicians to treat pain at the end of life.¹⁷ Specifically, the *Last Acts* report found that in 2000 only 59.7% of Maryland hospitals offered pain management programs, 25.8% provided palliative care programs, 19.4% provided hospice programs, and that referrals to hospice and length of stay in hospice are low.¹⁸ Unfortunately, the study did not assess how well pain was managed at the end of life. As a proxy for this measurement, in 1999, approximately

38.5% of Maryland nursing home residents reported persistent pain.¹⁹ Together, these statistics suggest the need for improvement in pain management for the constituents of Maryland.

This chapter addresses the status of cancer pain assessment and management in Maryland. Barriers to effective cancer pain management are described, including limitations in assessment, public awareness, access to services, and provider education and training. Health care disparities, issues related to reimbursement for pain and symptom management, and regulatory barriers are discussed. Rights and responsibilities, diversity considerations, the need for better coordination of pain management services throughout the health care system as well as across the disease trajectory, and the need for additional scientific research are highlighted. Several recommendations are provided that focus on improving access to, and use of, evidence-based assessment and multimodal therapeutic interventions, including complementary and alternative therapies. This assessment and therapy should be available and provided by multiple disciplines across the health care system to effectively manage cancer patients' pain and other symptoms.

Principles for Cancer Pain Assessment and Management

The following overarching principles are fundamental to the provision of quality cancer pain assessment and management to the citizens of Maryland:

Rights and Responsibilities: Patients, their providers, and the health care system as a whole have both rights and responsibilities regarding cancer pain assessment and management. Patients and their caregivers must be educated to understand the importance of cancer pain assessment and management, their role in that process, and to expect that cancer pain is monitored and treated as a routine part of care. The patient and caregivers must be included in health care planning since this increases adherence to prescribed regimens²⁰ and may improve the management of cancer pain. Health care professionals are responsible for advocating for effective pain relief for cancer patients and working within the health care system to advocate for system changes to provide effective cancer pain control to various patient populations that suffer from pain as a result of their disease process or injury. Health care providers should have access to pain specialists for con-

sultative purposes. Health care institutions and the systems that support them should provide structures that support a comprehensive pain management plan that includes informed consent. Health care providers have the right to adequate reimbursement for providing cancer pain care. Health care providers and systems have the right to information about minimum cancer pain management standards to which they will be held accountable. They also have the right to laws and regulations that support effective cancer pain management and must have access to information about strategies effective in improving cancer pain management. Several states and organizations have developed a Pain Care Bill of Rights (Table 14.1). Maryland has not yet instituted robust legislation to establish a Pain Care Bill of Rights for Marylanders.

Access and Advocacy: All cancer patients have the right to effective and affordable pain assessment and management services and therapies. Health care professionals must advocate for effective cancer pain relief. Advocacy is particularly important for populations that are known to be at greatest risk for ineffective cancer pain management (e.g., the uninsured, minorities, women, the elderly, and children) and for those who are unable to self-report or manage their own cancer pain related needs (e.g., due to dementia, age, disability, language barriers).

Cultural Sensitivity: Health care professionals and the systems in which they function must be sensitive to the pain perceptions and the expression of patients' needs as they are influenced by race, culture, religious and spiritual practice, sexual orientation, and economic status. Numerous health care studies demonstrate that the uninsured, minorities, women, the elderly, and children are at greater risk for under-treatment of pain. Details of these disparities are discussed later in this chapter. Specific attention to populations disproportionately affected by cancer pain is required in order to more effectively manage pain.

Barriers to Cancer Pain Assessment and Management

There are multiple reasons for the lack of effective cancer pain and symptom control. Cancer pain has been a neglected subject during professional training among physicians,²¹ oncologists,^{22,23} oncology nurses,²⁴ and other health care practitioners.^{25,26,27} This lack of training impacts routine systematic assessment and effective

Table 14.1
Pain Care Bill of Rights

As a person with pain, you have:

- the right to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other health care professionals.
- the right to have your pain thoroughly assessed and promptly treated.
- the right to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.
- the right to participate actively in decisions about how to manage your pain.
- the right to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.
- the right to be referred to a pain specialist if your pain persists.
- the right to get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

Although not always required by law, these are the rights one should expect, and if necessary, demand, for pain care.

Source: American Pain Foundation, 2003.

cancer pain treatment. There are multiple types of pain (e.g., somatic nociceptive pain, visceral nociceptive pain, bone pain, and peripheral neuropathic pain) that require that medications and non-pharmacologic therapy be directed at the specific type and etiology of the pain in order to be effective. Preferred drug lists and review processes, patient and clinician attitudes towards pain and pain therapies, providers' inexperience, insufficient referrals to pain specialists, lack of reimbursement for pain treatment, lack of access to appropriate health care and pain specialists, and cultural factors are all barriers which often impede effective cancer pain management.

Patient and Clinician Attitudes About Cancer Pain

A significant barrier to effective cancer pain management is patients' and clinicians' attitudes about pain and pain medication. Attitudes of patients and family members often result in reluctance to report symptoms to health care providers. Patients may fear that an increase in pain means their cancer has worsened, that it will distract the health care provider from cancer treatment, that pain is to be expected, or that they will be labeled a "bad patient." Cancer patients and their families may lack knowledge about options for effec-

tive pain management or may not be aware that they have the right to have their pain assessed and appropriately managed. Cancer patients and their families may have misconceptions: pain is inevitable, pain builds character, and complaints about pain distract the health care professional. Cancer patients may also fear the side effects of pain therapies. In addition, cancer patients may fear being perceived as weak for acknowledging their pain. In a survey conducted by the American Pain Foundation, 61% of Maryland respondents indicated that they did not seek help for their pain because they were embarrassed or didn't want to be seen as complaining.²⁸ These perceptions prevent them from seeking treatment.

The stigma associated with opioids and other powerful painkillers presents another barrier. Some patients cite fear of addiction^{29,30,31,32} as a reason for rejecting or reduced use of painkillers, but research has found that opioids decrease pain, increase function, and improve mood without causing addiction. Taking opioid medications for pain relief as prescribed, under the direction of a health care provider, is safe and effective and only in rare cases leads to addiction.³³

Provider Education and Training

Most physicians and other health care professionals receive limited training in pain management. Knowledge gaps, negative attitudes toward opioids, and inadequate assessment skills are all barriers to effective cancer pain management. The low priority given to pain treatment in professional training^{34,35,36,37,38} (including medical schools and residency programs) and educational texts³⁹ contributes to the problem. Senior medical students were found, in one study, to be reluctant to prescribe opioid therapy for pain.⁴⁰ Another study found them to be deficient in their understanding of multiple available options for relieving suffering in cancer patients.⁴¹ In addition, a recent study found pain management to be lacking among pharmacy school curricula.⁴² The training of doctors, nurses, pharmacists, and therapists in general is suboptimal regarding the thorough assessment and treatment of pain and other associated symptoms in patients with cancer.

Additional pain and symptom management content has recently been integrated into the curriculum at the University of Maryland School of Medicine and internal residency programs. Pain courses are also available as electives at the University of Maryland School of Nursing and School of Pharmacy. A palliative care pharmacy residency is also available. In addition, both Johns Hopkins University and the University of Maryland have pain fellowship programs. While Maryland professional schools may be on the forefront of training health care students in pain and symptom assessment and management, most clinicians practicing in Maryland have not completed their training in the state within the last few years. So most clinicians in Maryland were not exposed to adequate pain management training during their basic or advanced training. Postgraduate training for practicing health care providers may increase the use of effective methods of pain assessment and treatment,^{43,44} but often requires intensive mentoring, specialty programs, or the use of additional change strategies.^{45,46,47,48,49}

A two-pronged approach is required to facilitate pain management education for Maryland's health care professionals. Professional schools in Maryland should be required to have significant curriculum hours devoted to pain and symptom assessment and management, as should all residency programs. In addition, currently practicing health care providers should be required to complete additional training in this area through continuing education programs.

Preferred Drug Lists and Review Processes

Preferred drug lists and pre-approval processes are barriers to cancer pain management. Recent genetic evidence has confirmed long-standing clinical observations that medication is not "one size fits all." Genetic variations are responsible for the individual differences in pain medication response.⁵⁰ Some individuals may be incapable of metabolizing some analgesics into active compounds and thus may never obtain pain relief from certain medications. Other individuals are fast or slow metabolizers, causing varying analgesic response as well as impacting side effect profiles and severity. Testing for the genetic polymorphisms responsible for these individual differences is not currently available except in a research environment. This means that cancer pain treatment, including drug selection, must be individualized for each patient based on clinical response. Preferred drug lists and pre-approval processes hinder the health care practitioner's ability to tailor therapy and to provide timely, effective analgesia with manageable side effects.

Cultural, Ethnic, and Religious Factors

Cultural, ethnic, and religious factors are an important part of health care services, and their influence on cancer pain cannot be underestimated. A patient's culturally patterned understanding of the cause and interpretation of cancer pain will affect the course of the pain management plan. Religious or spiritual coping strategies may have an effect on the cancer patient's perception of pain. It is important to provide culturally competent care and to respect and maintain sensitivity to issues related to an individual's culture, race, sex, social class, economic status, and religious or spiritual coping strategies.

Comprehensive Pain Assessment Barriers

A comprehensive pain assessment is critical to provide health care providers with information for cancer pain management. Providers cite the lack of systematic assessment,⁵¹ subjectivity of the pain experience, and lack of time as the biggest obstacles to providing effective pain management. Routine screening using pain measurement tools can help health care providers determine when a patient is experiencing pain and thus respond to changes in pain, but simple pain screenings do not assess how pain affects that patient's life, the quality of the pain, when it occurs, or how much or what kind of medication(s) or other therapies will help reduce a particular patient's pain.

Pharmacy Barriers

Pharmacy issues can present barriers to pain management for people with cancer. Handling controlled substances that are used for cancer pain treatment poses several difficulties for pharmacies and pharmacists that are passed on to consumers as access issues, delays in therapy, or price increases. Specifically, staffing is required for security and record keeping of Schedule II pain medications. Governmental programs such as Medicaid often require overwhelming amounts of paperwork to dispense some controlled substances. The numbers of different medications, dosage size, form, and amounts needed may be difficult to estimate. Few discounts are available to pharmacies purchasing small quantities, resulting in little profit to small independent community pharmacies that may purchase opioids on an individual patient basis.⁵² While pharmacies must pay for medications up front, Medicaid may not reimburse pharmacies for several months. These issues show that there is little incentive for small pharmacies to stock some controlled substances, and this may adversely affect those individuals that depend on them, increasing disparities in the care of people in pain who are elderly, live in rural areas, or are in a low-income bracket.

Legal and Legislative Barriers

Pain management is also affected by legal and legislative barriers developed in response to concerns about drug abuse. Laws concerning controlled substances vary. In states with pain coalitions, efforts are being made to revise legislation to remove barriers to the use of opioids, such as removing dosage restrictions. A balanced approach to the dispensation of pain medication is needed so the effort to prevent drug abuse does not impede access of controlled substances to pain sufferers.^{53,54}

It is believed that careful attention to the assessment and effective treatment of pain and other symptoms of cancer patients is found more frequently among hospice patients than patients who have not been referred to a hospice program.^{55,56} Nationally and in Maryland, the average and median hospice lengths of stay are low.⁵⁷ This suggests late referrals to hospice, delaying access to effective pain and symptom management at the end of life that should have been available throughout the disease trajectory.

Disparities

Certain groups of patients face higher risks of unrelieved pain. Rural patients may not have access to pain specialists or pain clinics within a reasonable distance. Older people may view pain as an inevitable part of aging; some may have medical or cognitive conditions that may prevent them from describing their pain or following a pain management plan. Minorities, females, children, the elderly, and the underserved face significant risk for under-treatment of pain. Many of these patient populations have lower rates of insurance coverage and less access to health care. Minority cancer patients are at two to three times the risk of inadequate pain management than other cancer patients.⁵⁸ Factors that may be responsible for this disparity include cultural differences between providers and patients, language barriers, and length of time spent with providers. Physiologic mechanisms including drug metabolism may compound disparities in some populations. In addition, there is compelling evidence that health care professionals may unknowingly treat pain differently in these populations, resulting in under-treatment^{59,60,61,62,63,64,65,66} and increasing the previously mentioned disparities in care.

Health Insurance Policies and Reimbursement for Cancer Pain Care

Major contributors to inadequate cancer pain control include insufficient health insurance coverage, insufficient reimbursement rates,⁶⁷ inconsistency in health care benefits for pain control therapies provided by various health insurers⁶⁸ and increasing numbers of uninsured individuals.⁶⁹ Lack of health insurance coverage and uneven reimbursement policies for prescription drugs, medical equipment, and professional services inhibit access to cancer pain management.⁷⁰ Recent evidence suggests that effective cancer pain management may reduce cost of care, improve quality of life, and lengthen the lives of cancer patients.^{71,72}

Information on insurance coverage for pain management is sparse.⁷³ A recent study of 35 BlueCross BlueShield (BCBS) plan senior medical directors (SMDs) showed that most BCBS plans deal with pain coverage on a case-by-case basis and do not have uniform pain treatment or coverage guidelines.⁷⁴ Plan coverage for various pain treatments for the 35 BCBS SMDs is reported in Table 14.2. Although most plans

Table 14.2
Percentage of BCBS Plans Not Providing Various Pain Management Therapies

Pain management strategy	Percentage of plans not providing coverage (n=35)
Behavioral interventions	46%
Biofeedback	63%
Acupuncture	80%
Implanted pumps	17%
TENS (transcutaneous electrical nerve stimulation)	29%
Nerve Blocks	0

Source: Hoffman DE. Pain management and palliative care in the era of managed care: issues for health insurers. Journal of Law, Medicine, and Ethics 1998;26:(4)267-89.

have an in-house or out-of-house expert pain consultant, only a few plans indicated that their expert held board certification in pain management. Only 13 plans reported that they had addressed pain management in the terminally ill.

Data regarding pain management reimbursement by commercial payors and HMOs primarily consists of anecdotal reports by health care providers.⁷⁵ These providers report repeated submission and substantiation of pain management treatment plans prior to reimbursement or preauthorization by payors.⁷⁶ Critical components of the pain management treatment plan may be denied^{77,78} or inconsistently approved.⁷⁹ This indicates the comprehensive, multidisciplinary approach that is required to effectively manage many cancer pain problems is not understood by payors or their experts.

Little information exists about the impact of Medicaid policies on pain control for cancer patients. Medicaid reimbursement for end-of-life care is known to be inadequate in providing advanced types of pain relief such as chemotherapy, radiation treatments,⁸⁰ and specialized analgesic therapy. Pain treatments available for Medicaid reimbursement vary based on setting (e.g., home, nursing home, or hospital) and services provided (e.g., hospice or acute care) and, to a degree, are state regulated.⁸¹

Medicaid cancer patients may receive more pain medications and more effective pain medication than patients covered by some other insurers because Medicaid provides pharmaceutical benefits.⁸² A recent initiative in Maryland to restrict the Medicaid formulary has the

potential to deny patients access to certain pain medications and impede effective cancer pain management. Preferred drug lists and review processes are system barriers⁸³ that hamper effective cancer pain treatment. Preferred drug lists and pre-approval processes are believed to increase the reluctance of health care providers to prescribe effective pain therapy and is therefore likely to impede the provision of timely, effective pain management.

Similar to Medicaid, few studies have used Medicare data to assess reimbursement for pain management strategies. Several issues may affect access to, and payment of, cancer pain management therapies by Medicare. The lag time between the introduction of new drugs and adjustments to Diagnosis Related Groups (DRG) and Resource Utilization Groups (RUG) used in acute care settings and nursing homes can be two years or greater,⁸⁴ reducing access to new treatments. Medicare coverage is also subject to a reasonable and necessary test based on the patient's clinical condition, which can result in significant variability in coverage decisions across the United States.⁸⁵ Medicare limits its payment for physician's services for pain management, and this is believed to deter adequate treatment.⁸⁶ Under Medicare, injections cannot be billed separately unless no other physician services are billed at the same time.⁸⁷ Bundling of pain management in post-operative services⁸⁸ also deters the use of specialists in the provision of effective pain management^{89,90,91} and may be partially responsible for continual problems of uncontrolled post-operative pain, premature discontinuance from specialized analgesic therapy, and untoward effects from specialized analgesic therapies.⁹²

Medicare does not provide coverage for self-administered outpatient medications other than for patients electing the Hospice Medicare Benefit. Although there is some limited coverage for home infusion of medications,⁹³ the lack of an outpatient drug benefit may mean that more expensive invasive pain treatments may be substituted for simple, more cost-effective oral regimens. Regardless of the route of analgesic therapy, lack of prescription coverage may negatively impact the control of analgesic side effects and detrimentally affect pain control. In addition, side effects, which are most often treated with other oral medications, have been shown to decrease patient adherence to prescribed pain medication regimens and are believed to be partially responsible for the continued problem of inadequate pain control.⁹⁴

Some analysis of the Medicare hospice benefit has been performed. While Medicare's hospice benefit provides outpatient medications, a recent survey of hospice programs suggests that low payment rates make it difficult to provide expensive treatments such as palliative radiation and chemotherapy, effective modalities to provide pain control in the cancer patient.⁹⁵ Fixed per diem rates may also limit hospice patient access to newer, more costly medications⁹⁶ and may require a change in therapy when a patient switches to the Medicare Hospice benefit. Anecdotal evidence also suggests hospice formularies and specialty analgesic therapies are restricted in an effort to reduce costs.

Many people in pain never see a pain specialist. Primary care providers may not refer patients to specialists or to other members of the multidisciplinary pain team.^{97,98} Last but not least, a separate rider may be required for beneficiaries to obtain coverage for medications. For those with prescription drug benefits, any limitations on prescriptions, network pharmacy restrictions, and caps on prescription drugs also limit access to effective pain management.

With new knowledge and rapidly changing technologies, consideration must be given to ensuring that cancer patients have access to pain management specialists and effective therapies. Since a full range of pain management modalities is cost effective,⁹⁹ they should be available to individuals regardless of the illness trajectory, health insurance, setting, or election of special services (e.g., acute care or hospice). Access to a wide variety of pain control options and medications is necessary because of the highly individual nature of pain, wide variety of clinical conditions, and varied responses to pain related treatments.

Pain Management Standards

The Institute of Medicine report, "Priority Areas for National Action: Transforming Health Care Quality,"¹⁰⁰ targeted pain control in advanced cancer as a priority area. The authors concluded that improving pain care would allow all stakeholders to improve the quality of health care and reduce disparities. Although several guidelines, such as the World Health Organization's analgesic ladder, have been validated, cancer pain continues to be under-treated due to inconsistencies among various health care systems. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) implemented pain management standards in 2000 and added them to all their organizational manuals. The essential components addressed by the JCAHO standards are:¹⁰¹

- Individuals have the right to appropriate assessment and management of pain.
- Assess the existence of and, if present, the nature and intensity of pain in all patients, residents, or clients.
- Establish policies and procedures that support the appropriate prescribing or ordering of effective pain medications.
- Educate patients, residents, and clients and their families about effective pain control.
- Address the individual's needs for symptom management in the discharge planning process.
- Incorporate pain management into the organization's performance measurement and improvement program.

Facilities within the health care system involved in assessing or treating patients in pain should be held to consistent standards of quality pain management regardless of their accreditation. Unfortunately, many licensed health care facilities that care for cancer patients are not accredited by the JCAHO, including extended care facilities, nursing homes, freestanding radiation oncology centers, hospices, home health agencies, pain clinics, and physician offices. These facilities should have pain assessment and management standards similar to JCAHO standards enforced by the applicable licensing or accrediting agency. The Wisconsin Cancer Pain Initiative has developed guidelines to assist organizations in their efforts to institutionalize pain management. The eight steps essential in implementing this approach are:¹⁰²

- Develop an interdisciplinary workgroup.
- Analyze current pain management practices in your care setting.
- Articulate and implement a standard of practice.
- Establish accountability for pain management.
- Provide information about pharmacologic and nonpharmacologic interventions to clinicians to facilitate order writing and interpretation and implementation of orders.
- Promise individuals a quick response to their reports of pain.
- Provide education for staff.
- Continually evaluate and work to improve the quality of pain management.

In Maryland, there is inconsistency among licensing boards in the development of statements outlining each profession's role in the assessment and management of pain, subsequent monitoring and interventions regarding adherence to standards, and dissemination of related information to professionals.

When all health care professionals and facilities are held to similar pain management standards, the quality of pain management can be sustained as patients transition between health care settings. Moreover, accountability for pain management will then be clearly defined throughout the health care system.

Complementary and Alternative Medicine

Complementary and alternative medicine, as defined by the National Center for Complementary and Alternative Medicine (NCCAM), is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.¹⁰³ "While some scientific evidence exists regarding some complementary and alternative medicine (CAM) therapies, for most there are key questions that are yet to be answered through well-designed scientific studies—questions such as whether they are safe and whether they work for the diseases or medical conditions for which they are used."¹⁰⁴

Therapies used jointly with traditional medicine, such as aromatherapy to lessen a patient's post-surgery discomfort, are considered complementary therapies. In contrast, alternative therapies are used as a substitute

for conventional treatments. For example, the use of a special diet to treat cancer instead of undergoing conventionally recommended surgery, radiation, or chemotherapy is considered an alternative therapy.¹⁰⁵

Integrative medicine, as defined by NCCAM, combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness.¹⁰⁶ Ongoing research regarding the efficacy and appropriateness of CAM therapies in cancer pain management should be encouraged and supported. The use of scientifically validated complementary and alternative therapies for pain control should be supported as individual measures or in conjunction with traditional pain management methods. To that end, patients and providers must discuss how CAM therapies may be integrated into their overall pain management. In addition, reimbursement of these therapies by insurance companies is necessary to allow their use in the cancer patient population.

Research

There is a lack of research and knowledge in the area of cancer pain. In a recent NIH State of the Science Conference—Symptom Management in Cancer: Pain, Depression, and Fatigue, key research findings and future research avenues were identified and included in an evidence-based report.¹⁰⁷ Specifically, epidemiologic characteristics, including details regarding the various types of cancer pain, have not been adequately described. A minimalist approach to assessment of pain and analgesic side effects has been utilized, despite voluminous literature that suggests a more robust approach. Major gaps exist in the knowledge about therapeutics, such as relative efficacy of analgesics, adjuvant therapy, surgical interventions, non-invasive therapies, non-pharmacological treatments, and palliative care regimens. The NIH State of the Science conference also suggested pain be assessed in conjunction with other symptoms such as depression and fatigue as symptom clusters.

Many pain treatment guidelines have not been validated by research. Little information exists on procedural pain and its management in a population that undergoes a multitude of painful procedures. There are insufficient studies available to guide appropriate assessment and treatment of pain in special populations, such as children, the elderly, or the cognitively impaired.

Additional topics and specific considerations for con-

ducting cancer pain research are identified in the NIH State of the Conference evidence-based report,¹⁰⁸ as well as recent Agency for Healthcare Research and Quality evidence reports.^{109,110} It is vitally important that funding for future cancer pain research and study be identified and promoted. For example, pharmaceutical companies should be encouraged to continue research and development of new treatments for the management of cancer pain. Insurers should be solicited to fund and provide data for epidemiological studies regarding the prevalence of cancer pain among patients in Maryland. Funding should be allocated to assist in the assessment of new or existing statewide policies regarding their impact on cancer pain control.



Pain Management Goals, Objectives, and Strategies

Goal:

To increase awareness of, and access to, comprehensive pain assessment and management services for all cancer patients in Maryland in light of the current public health crisis of inadequate pain control.

Target for Change

By 2008, develop a system to monitor the availability and quality of pain assessment and management services for cancer patients in Maryland, with specific attention to the needs of special populations, including pediatrics and minorities.

Objective 1:

Increase provider awareness and training regarding appropriate cancer pain assessment, management, and relevant regulatory issues.

Strategies:

1. Provide cancer pain management education to all target audiences, which include, but are not limited to, health care systems, licensing boards (including investigators), professional organizations, ethics committees, Ombudsmen, state surveyors, regulators and reviewers, the Inspector General, the Insurance Commission, the Attorney General, criminal justice officials, medical examiners, and insurers.
2. Require all cancer health care providers (including, but not limited to, physicians, nurses, and pharmacists) to earn continuing education credits in the area of cancer pain assessment and management before license renewal.
3. Health care students in all disciplines should receive both didactic and clinical training in cancer pain assessment and management standards before receiving licensure. This training includes, but is not limited to, disparity issues in cancer pain management and topics related to licensure and cancer pain control as well as drug utilization and surveillance utilization review. The educational curriculum should be assessed by pain management experts, use multiple educational formats, and be accompanied by an assessment of knowledge and competency on an ongoing basis.
4. Each licensing board should develop a statement about their discipline's role in cancer pain assessment and management, including minimum competencies and education requirements. Such documents should be developed with the input of pain specialists and address issues of pain management and licensure. Providers should be required to view the statement prior to licensing or reciprocity. The



statement should be broadly available including via electronic media and accompanied by practitioner educational efforts.

5. Professional licensing boards should be encouraged to treat transgressions of untreated or under-treated cancer pain aggressively. Appropriate remedial education should be made mandatory prior to actions against a practitioner's professional license.
 - Evidence-based guidelines (e.g., Federation of State Medical Boards guidelines)¹¹¹ and pain experts should be used by licensing boards and the state drug enforcement agency to investigate cancer pain or analgesic-related issues.
6. New policy and legislation relevant to cancer pain assessment and management should be accompanied by educational initiatives targeting appropriate audiences.
7. Increase provider awareness of scientifically validated complementary and alternative cancer pain therapies, and encourage providers to discuss these therapies with their patients.

Objective 2:

Increase provider reimbursement for cancer pain therapies.

Strategies:

1. Recommend that insurers in Maryland provide a uniform pain assessment and management benefit for all age and income groups that would include, but would not be limited to:
 - inpatient and outpatient referral to a pain specialist for pain assessment and treatment planning, short and long-term multimodal treatments and follow-up, including management of side-effects.
 - Follow-up by licensed health care professionals including non-prescribers (e.g., home health nurses, clinical specialists) to provide education, assess adherence, and work with the patient and his/her caregivers and the prescriber to maximize pain management therapy.
 - Uniform minimal reimbursement for pharmacologic and scientifically based non-pharmacologic pain management therapies regardless of therapeutic medication class, choice of drug or therapy, method of medication delivery (i.e. route), site of service, or disease phase. Therapeutic interventions to manage pain including palliative pain interventions (chemotherapy, radiation therapy, and radioisotope therapy), pharmacologics (long- and short-acting analgesics, adjuvants, and side-effect medications), non-pharmacologics (e.g., physical therapy, acupuncture, and behavioral interventions), interventional procedures (e.g., temporary and permanent nerve blocks) and associated durable medical equipment, should be included in uniform minimal reimbursement standards.



In the development of this mandated benefit, consideration should also be given to:

- minimizing drug premiums and co-pays while keeping the benefit sustainable and attractive.
 - assuring uniformity of coverage across the Medicare and Medicaid programs and coordination of benefits between these programs, including hospice.
 - the components and effect of Medicaid drug utilization review (e.g., the impact of regulations regarding limiting drug quantities, refills, co-payments, the number of allowed prescriptions per month, and pharmacy dispensing fees; provider prescribing practices; referrals to Medicaid Fraud Control Units or Surveillance and Utilization Review programs).
 - facilitating seamless, timely, and adequate reimbursement of claims.
 - rapid assessment of new therapies by a team of pain experts for inclusion in minimum uniform coverage benefit.
2. Extend assistance for pain therapy payments for patients at or below 250% of the federal poverty level.
 3. Encourage insurers to offer a discount on malpractice insurance for providers who have completed continuing education in the area of cancer pain assessment and management and demonstrate competency in this field.
 4. Advocate for reimbursement of scientifically validated complementary and alternative pain therapies by insurance companies.
 5. Insurance contracts should be required to specifically provide current and prospective plan subscribers with information about the pain management services provided by the plan.

Objective 3:

Increase consistency among different health care systems regarding compliance and adherence to standards for cancer pain assessment and management.

Strategies:

1. Develop and test an external source of norms to which all health care facilities assessing or treating cancer patients in pain would be held accountable. Licensed health care facilities not accredited by the JCAHO (e.g., extended care facilities, nursing homes, freestanding radiation oncology centers, hospices, home health agencies, pain clinics) should be held to pain assessment and management standards similar to JCAHO standards by the applicable state licensing agency. Financial reimbursement should be tied to meeting these quality standards.
2. Reduce limitations to prescribing cancer pain medications (e.g., specific dose required instead of a dose range) and medications for side effects (e.g., use of haloperidol for nausea and vomiting) in extended care facilities.
3. Promote institutional scrutiny for disparity-related cancer pain management issues.
4. Information about a patient's cancer pain management regimen should be transferred with any discharge or transfer of care.
5. Develop standardized definitions of service scope for cancer pain specialists and cancer pain treatment centers.
6. Promote the use of population specific, standardized, reliable, valid, cancer pain assessment tools. Special consideration should be given to the effect of cancer pain on patient function and to patients with limited ability to communicate or advocate for themselves (e.g., children, people with language barriers, patients with dementia).

**Objective 4:**

Eliminate barriers due to cultural, age, sex, and income disparities and ensure equal access to cancer pain management therapies within the health care system.

Strategies:

1. Convene an independent committee to improve and accelerate the process relative to prior authorization of non-formulary medications and invasive techniques used in cancer pain management. The committee should work to reduce excessive copayments for non-formulary medication if the non-formulary medication provides the best results for a particular patient.
2. Pharmacies should be required to have pain management medications, particularly opioids, readily available for patients.
3. Ensure that excessive restrictions do not exist on the amount of medication prescribed, prescription renewals, and telephone, fax, or other electronic prescription ordering of analgesics for cancer pain.
4. Encourage the establishment of multidisciplinary cancer pain treatment centers employing pain specialists in multiple health care disciplines.
5. Draft legislation that requires cancer patients with unrelieved pain to be referred to cancer pain specialists in a timely fashion and guarantees that information about cancer pain treatment plans is communicated between providers and institutions at the time of discharge or transfer.

Objective 5:

Increase scientific knowledge regarding assessment and treatment of cancer pain.

Strategies:

1. Encourage and promote research in such areas as:
 - cancer pain assessment tools, particularly for minority populations and populations that are unable to advocate for themselves because of limited communication skills.
 - low-cost medications for cancer pain management (e.g., methadone).
 - outcomes analysis (e.g., long term opioid use; opioid rotation, tolerance, and addiction; cancer pain quality tools for use by surveyors and accrediting organizations; and the financial as well as quality impact of recommendations made herein and associated legislative changes).
 - cognitive, behavioral, complementary, and alternative cancer pain therapies.
 - guidelines for the assessment and management of specific types of cancer pain (e.g., neuropathic pain).
 - when to refer patients to cancer pain specialists and the accompanying credentials for certification of such specialists.
 - pediatric cancer pain management.
 - changing clinical practice and clinicians' fear of regulatory scrutiny.
 - improving patient adherence to cancer pain therapy.
 - occurrence of cancer-related pain by cancer, stage, type of cancer pain, and other factors such as demographics and longitudinal trajectory.
 - use of medical marijuana for cancer pain.



2. Encourage pharmaceutical companies to continue research and development of new treatments for the management of cancer pain.

Objective 6:

Increase public knowledge and awareness of cancer pain management practices and referral sources.

Strategies:

1. Partner with organizations such as the American Cancer Society, the American Chronic Pain Association, the American Pain Foundation, and the Maryland Pain Initiative to conduct a comprehensive, statewide, and culturally sensitive public health campaign to promote cancer pain assessment and management. This effort should utilize public health strategies and include an educational media campaign. The message should include a focus on patients' rights to adequate cancer pain management and their health care providers' responsibilities in the process as well as their own responsibilities, dispel myths about pain medications, describe options that exist for cancer pain management, and instruct the public to communicate with their health care provider about cancer pain.
2. Provide culturally sensitive and language-appropriate cancer pain control information to all patients and/or their surrogate at the time of diagnosis and throughout their disease process. Consider the use of educational materials already in existence from organizations such as the American Cancer Society and National Cancer Institute. As part of this effort, develop a mechanism to disseminate standard, medically appropriate information on specific cancer pain medications and therapies to patients. Seek to inform patients and/or surrogates of options, alternatives, and potential outcomes and involve them in treatment selection.
3. New policy and legislation relevant to cancer pain assessment and management should be

accompanied by educational initiatives targeting the general public.

4. Develop and make available in a variety of media a list of Maryland cancer pain resources including, but not limited to, pain specialists, pain experts, pain clinics, hospices, medical schools, and pain specialty consumer groups.
5. Develop, staff, and publicize a pain management hotline for cancer patients and health care providers.

Objective 7:

Enhance existing legislation and create new regulations designed to increase awareness of, and access to, comprehensive cancer pain assessment and management services for all cancer patients in Maryland.

Strategies:

1. Revise the advanced directive and living will forms for clarity. Make the power of attorney (POA) form the lead form provided to cancer patients and consider eliminating the living will in favor of a revised advanced directive. Instructions should be written to strongly favor POA, supported with more specific guidance if the declarant wishes.
2. Modify state regulations to facilitate availability and prescribing of cancer pain medications.
3. Modify state regulations to mandate that insurers in Maryland provide a uniform cancer pain assessment and management benefit for all ages, income groups, phases of the disease trajectory and regardless of site of care (see Objective 2).
4. Allocate funding to assist in the assessment of relevant, new, or existing statewide policies regarding their impact on cancer pain control.
5. Develop a Cancer Pain Patient's Bill of Rights based on a similar California bill (1997) CAHLTH & S 124960. This bill should include:



- some mechanism of enforcement.
 - a recommended course of action if an individual is denied cancer pain care.
 - a requirement for regular assessment and charting of cancer pain in physicians' offices, health care clinics, and licensed health care facilities.
 - A provision that licensed health care facilities as well as clinics, treatment centers, home health agencies, hospices, and physicians' offices adhere to an external cancer pain assessment and management standard that defines minimum practice and quality monitoring requirements.
 - a requirement for transfer of cancer pain-related information when care is transferred (e.g., at discharge, between providers, or among institutions).
 - A requirement that patients receive an explanation of cancer pain management options, alternatives, and potential outcomes and are involved in treatment selection.
6. Provide funding for the educational initiatives put forth in this document.
 7. Provide regulatory structure and legislative support for policy initiatives put forth in this document.

Note: Under-treatment of pain is a public health problem, regardless of the underlying etiology. Hence, the issues related to cancer pain apply to pain in general. Like all pain, cancer pain can be acute or chronic, assessment and management is often inadequate, and the related cultural and psychological issues and barriers are similar in both malignant and non-malignant pain conditions. Therefore, it is suggested that the recommendations in this chapter be extended to the management of acute and chronic pain and associated symptoms of non-malignant conditions so that all the citizens of Maryland, whether or not they have cancer, may benefit from the goals, objectives, and strategies suggested here.

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CHAPTER 15

END-OF-LIFE CARE



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END-OF-LIFE CARE

Despite improvements in prevention, early detection, and treatment, cancer remains a terminal illness for many patients. About half of all patients diagnosed with cancer will die from their illness within a few years of presentation.¹ In 1999, more than 10,000 Maryland residents died from cancer.

Maryland ranks eleventh in the nation in cancer mortality.²

Cancer care must be as patient-centered during the last phase of the illness as when the emphasis is on cure. Indeed, cancer and end-of-life care have been intertwined since the beginning of the hospice movement. Techniques in palliative medicine for managing pain, dyspnea, bowel obstruction, and other symptoms typically were developed for the care of cancer patients and later were adopted for patients with non-cancer diagnoses.³

The principles that should govern cancer care at the end of life are well-accepted in the field. They include responsiveness to the patients' wishes; truthful, sensitive, empathic communication; and meticulous attention to the physical, spiritual, and psychosocial needs of patients and family.⁴

The vision underlying these principles, however, is often not reflected in the dying individual's reality.

Hospice care directly furthers these goals and allows patients to die in settings that make achieving these principles more likely.⁵ However, of all Marylanders over 65, only 20.5% used hospice services in the last year of life (2000 data); of those who use hospice services, the median length of stay was a mere 20 days (2001 data).⁶ However, hospice is not the only means by which cancer patients can receive excellent palliative care. For example, hospitals can provide these services, but only a quarter of Maryland hospitals offered a palliative care program in 2000.⁷ It is evident that new and improved models are needed to fit the needs of the diverse populations who die from cancer and to support their families and social networks.

This chapter considers various aspects of the gap between the care that ought to be given to cancer patients as life nears its end and the care that they actually receive. This chapter describes barriers and shortfalls with respect to access to care, reimbursement, public and provider education, and research and suggests ways to integrate approaches to end-of-life care.

Access to End-of-Life Care in Maryland

Very few Americans understand the options available for end-of-life care for themselves and their loved ones. Even fewer take advantage of these options. Much of the data about this issue comes from the hospice movement. In a 1999 survey conducted by the National Hospice Foundation, 80% of Americans did not know the meaning of the term "hospice."⁸ Indeed, 75% of Americans were unaware that hospice care can be provided in the home, and 90% did not realize that hos-

pice care is fully covered though Medicare. This same survey also indicated that most Americans desire the type of end-of-life services offered by hospice.⁹

Hospice is a model of care that provides palliative care to patients with life-threatening medical conditions. The hospice model recognizes the need to care for the whole person, including mind, body, and spirit, and to support those who love and care for terminally ill persons. Hospice care can be provided in a variety of settings, including hospitals and nursing homes. However, in the United States, hospice services are most commonly provided at home.¹⁰ Traditionally, hospice has been associated with cancer patients and 63% of diagnoses upon admission to hospice care in Maryland were for cancer compared to 57% nationwide in 2000.¹¹ Although cancer patients and their caregivers continue to be the primary users of hospice care, trends indicate that patients with non-cancer diagnoses, including end-stage heart or lung disease, Alzheimer's disease, or AIDS are increasing their use of hospice services.¹²

The underlying principle of hospice is palliative care, which focuses on improving the patient's physical comfort and quality of life. Patients receiving palliative care should be able to continue to treat their disease with curative interventions, though it is common for health care systems and practitioners to view palliation as being in conflict with curative efforts. In whatever setting it is administered, palliative care is generally provided by an interdisciplinary team, which may include physicians, nurses, social workers, home health aides, pharmacists, chaplains, physical and occupational therapists, and trained volunteers. A growing number of hospitals are beginning to understand the importance of palliative care and are offering inpatient palliative care services.¹³ However, many end-of-life care providers continue to be concerned about what they call "the irrational choice" patients face in having to relinquish curative options in order to access hospice services. "The either-or approach that was adopted as a cost containment measure imposes a simplistic binary-decision model that is not consistent with either the clinical or emotional reality of the hospice process for patients and their families," according to David Rehm, President and Chief Executive Officer of VistaCare Hospice Foundation.¹⁴

Many patients experience limited access to services due to gaps in the continuum of end-of-life care. An uncertain prognosis or desire to continue with curative efforts while receiving palliative care can present significant barriers to quality end-of-life care. There is a great need for our

health care system to create an end-of-life care model that includes "interdisciplinary teams, continuity and coordination of care, integration of diverse services delivered in a variety of settings, and changes in the orientation of providers."¹⁵ Currently, our health care system fails to care for those with advanced illness by rarely providing a bridge between acute and end-of-life care. Medicare is criticized for the way it funds end-of-life care, including its focus on the provision of acute services and its packages of post-acute services that function as barriers to a seamless continuum in the last stages of life.¹⁶ The tie between prognosis and reimbursement is discussed in further detail in the next section. Often, patients with significantly better prognoses than a typical hospice patient have needs for supportive care that are at least as great, if not greater, than patients already in hospice. Prehospice or "bridge" programs offer patients some of the services of hospice without eligibility restrictions such as a six-month prognosis or forgoing curative therapies.¹⁷ There is a great need for development of these and other creative programs for administering multidisciplinary supportive care for cancer patients, regardless of their prognosis or decisions regarding curative interventions.

There is considerable need to identify patients within all health care settings, especially acute care settings, who may benefit from hospice or similar palliative approaches to care. Analysis of information gleaned from surveys of case managers and administrative databases justified enhanced attention to inpatient palliative care consultation, as well as consideration of the need for acute palliative care inpatient units.¹⁸ Unfortunately, most Maryland hospitals lack hospice or palliative care programs. In 2000, only 19.4% of hospitals in Maryland reported that their services include a hospice program, and only 25.8% of hospitals reported that they offer a palliative care program.¹⁹

Hospitals in Maryland treat a high percentage of critically ill patients in intensive care units (ICUs), which emphasize high-technology treatments, even when a patient is unlikely to recover. This is demonstrated by the 12% of elderly Maryland residents who spent a week or more in an ICU during the last six months of life. This also suggests that health care providers may prescribe overly aggressive treatments that do not take the patient's wishes into consideration and may prolong his or her discomfort.²⁰ Long stays within an ICU are extremely expensive and are often followed by death or disability, the primary motivators for treating the patient aggressively in the first place. In an analysis of patients enrolled in the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments), median hospital costs were

\$76,501 for patients who had ICU stays of 14 days or longer and \$10,916 for patients with shorter ICU stays. In addition, among the patients who preferred a palliative approach to care, only 29% thought that their care was consistent with that aim.²¹

As of 2002, there were only 34 licensed hospice facilities in Maryland, with a total of 89 inpatient beds to service the entire state.²² All of these beds are located in areas surrounding Baltimore or Washington, D.C., which leaves the vast majority of state residents without convenient access to nearby inpatient hospice services. The majority of these facilities hold a general license (i.e. they provide skilled medical nursing and palliative, psychological, social, and spiritual support to patients and may be in a home-based setting or in a variety of inpatient locations) and not a limited license, which permits non-skilled palliative and supportive services only in home-based settings.²³ While most Maryland counties are served by some form of hospice care, there is an immense shortage of inpatient hospice beds. In addition, there are limited or no beds available for patients under the age of 18 years in most areas of the state.

Marylanders may benefit from enhanced partnership among hospices and long-term care facilities such as nursing homes and assisted-living facilities. In recent years, nursing homes have received increasing criticism for their failure to properly attend to pain and other supportive care needs of dying patients, especially those with cancer.²⁴ Thus, these and other facilities may seek to improve their palliative care services through partnership with hospices. Greater hospice presence in nursing homes may allow identification of the palliative care needs of patients that would otherwise go unrecognized and also provide education to clinicians and other nursing home staff regarding end-of-life care.²⁵

In Maryland, only 26.7% of state residents die at home based on data from 1997,²⁶ though it is well documented that most Americans would prefer to die at home. However, combined data from 1997–2000 indicates that Maryland is doing somewhat better in regard to location of death for cancer patients, with 38.7% of deaths occurring in the patient's residence.²⁷ However, over half of cancer patients in Maryland (50.9%) died in a hospital or nursing home setting during the same time period.²⁸ If these facilities do not offer appropriate palliative care services, then many Marylanders may not receive comprehensive end-of-life care.

The length of a patient's stay within a hospice facility is another significant indicator of the availability of appro-

priate end-of-life services. A minimum sixty-day stay is considered necessary for the patient to receive maximum benefit from the hospice program.²⁹ Unfortunately, the actual length of stay for many hospice patients is significantly shorter than 60 days. Nationally, the average length of time a patient receives hospice services has declined from 64 days to 48 days from 1992 to 2000. Over the same time period, the median length of time a patient receives hospice services in the U.S. has decreased from 29 to 25 days. The median length of stay in hospice care is generally accepted as a more accurate way to understand the experiences of typical hospice patients, due to the high frequency of short stays.³⁰ Maryland's median length of stay was a mere 20.5 days for 2001, even less than the national median.³¹

The most significant barrier to effective utilization of hospice services may be its rising operational costs. In part this is because of dramatic improvements in palliative care that have reduced the duration of care provided to hospice patients. Many palliative treatments have become easier to provide in a home setting, which has driven up outpatient costs. Decreasing lengths of stay have increased costs to hospice due to patients seeking hospice care later in their terminal illness, creating a shorter period over which to balance the high cost of care. In addition, the demanding nature of hospice work coupled with limited resources may contribute to low staff satisfaction and retention. This puts hospice care providers at a particular disadvantage in a field where shortages of nursing staff are endemic. To balance these shortages, hospices have had to concentrate more effort on fundraising, which places additional burdens on hospices as well as the communities that support them.³²

Much of the accessibility of end-of-life care is determined by the overriding attitudes and culture of the health care system. Persons with advanced disease tend to represent failure to the health care system. Increasingly, it is crucial to understand how patients with advanced illness want to spend the rest of their lives. It is important for policy makers to change their focus from a procedure- and pharmacy-oriented health care system to a continuum of care that ensures those with chronic illness have a range of options from which to choose. “Only then will the definition of ‘success’ in caring for persons with advanced illness begin to gradually take on new meaning; the degree to which the quality of patients’ lives is enhanced and their suffering relieved will become a measure of success.”³³

Disparities

Although end-of-life care is improving in the U.S., these improvements have been slow to impact the African-American and other minority communities. It has been well documented that African Americans in particular underutilize palliative and hospice care services. African Americans make up 13% of the total U.S. population, but only 8% of hospice patients.³⁴ Maryland has a higher rate of minority participation in hospice than the U.S. (approximately 16%). However, participation by minorities varies by region across Maryland. In Prince George's County, where 74% of the population is non-white, only 53% of hospice patients are non-white. In Montgomery County and on the Eastern Shore, the ratio of the non-white population to non-white hospice patients indicates that non-whites utilize hospice at a higher rate than whites. Despite these variations, hospices generally experience less minority participation than non-minorities. Cultural differences may contribute to the lower overall use of hospice services of these various populations.³⁵ Socioeconomic disparities also exist in end-of-life care, and are often indicated by the location of a patient's death. In a recent national study of where people die, decedents who were black, less-educated, and enrolled in an HMO were more likely to die in a hospital,³⁶ though it has been shown time and again that most Americans would prefer to die at home.

Pediatric Care

Disparities in end-of-life care for pediatric patients also exist. Children are often diagnosed with more advanced stages of cancer than adults; 80% of children have metastases at diagnosis, while only 20% of adults have advanced cancer at diagnosis.³⁷ And while the number of children diagnosed with cancer is certainly lower than adults (approximately 8,000 children under the age of 15 are diagnosed nationally each year, about 0.6% of all cancer diagnoses), this number threatens more years of life than any single type of adult cancer.³⁸ The most common childhood cancers are hematologic malignancies (leukemia). Children with leukemia are more likely to die from therapy-related conditions such as infection, while patients with solid tumors are more likely to die from their disease.³⁹ Thus, providing end-of-life care for children with cancer that meets the unique needs of these patients and their families is crucial. Families need access to quality pediatric hospice programs, as well as excellent palliative care programs within hospital settings.

In Maryland there are few hospice programs with staff specifically trained in pediatric end-of-life care. Hospice regulations were originally designed for adult cancer patients dying from their disease rather than therapy-related conditions, so parents of pediatric patients are often forced to make an "all or nothing" choice—either choose hospice services or continue with therapies. This is the same choice many adult cancer patients face when deciding between the continuation of curative efforts and hospice care. Many children also die in the hospital setting and these patients and their families deserve the best care possible in this situation, including staff trained in end-of-life care, psychosocial, spiritual, and bereavement support. It is often difficult to find and retain staff that is able to work with terminally ill children.⁴⁰

Reimbursement for End-of-Life Care

In palliative care, as in most of American medicine, services that meet a patient's needs are available only to the extent that a funding mechanism pays for them. Payment mechanisms include the hospice benefit under the federally funded Medicare program; the hospice benefit under the Medicaid program, which is funded jointly by federal and state governments; and hospice benefits under private health insurance, which is subject to state regulation. Given the epidemiology of cancer, Medicare is the most important source of payment for palliative care services, but the scope of Medicaid and private insurance is of particular concern for pediatric patients requiring end-of-life care.

When the Medicare hospice benefit was adopted in 1983, some heralded it as "the gold standard of end-of-life care".⁴¹ This characterization is based on the fact that the hospice benefit includes many services that are not typically part of Medicare coverage, including care planning, personal care nursing, medication, family support, chaplaincy, and bereavement counseling.⁴² However, the hospice benefit gained approval by Congress only on the basis that it would not add substantially to Medicare's costs.⁴³ Consequently, qualification for the benefit is narrow. A patient qualifies only by agreeing to forgo curative treatment for cancer or other terminal illness, and the patient's physician must certify that the patient's life expectancy is six months or less if the disease runs its normal course. The continuation of therapy, including chemotherapy intended for palliation of symptoms, is often not allowed at all, or permitted only after prolonged negotiations with Medicare representatives.

This “either/or” choice effectively bars access to a range of palliative care services for patients who could benefit from them but who are not ready (or whose physicians are not ready) to concede that curative efforts ought to be abandoned. The culture of high-tech cancer care has had difficulty assimilating the idea that a good death is part of good cancer treatment;⁴⁴ the terms of the Medicare hospice election only reinforce the false dichotomy between treatment and palliation. Moreover, physicians who are unsettled by such a specific prognosis requirement, and who fear regulatory scrutiny if a patient lives “too long,” delay hospice referral. In the words of one hospice association official, “It’s just so very difficult to say when . . . the six-month clock is going to start ticking . . . and the result [is that] the referral occurs about two weeks before the death.”⁴⁵

By contrast, Maryland law on hospice benefits does not incorporate an explicit, time-linked prognosis prerequisite. The statute that sets up the basic framework for the Medicaid Program authorizes the Department of Health and Mental Hygiene (DHMH) to reimburse “for services provided by a hospice care program,” as defined elsewhere in state law.⁴⁶ That definition, in the part of the law requiring licensing of hospice programs, refers to “a coordinated, interdisciplinary program . . . for meeting the special physical, psychological, spiritual, and social needs of dying individuals and their families . . .”⁴⁷ The “dying” are those “who have no reasonable prospect of cure as estimated by a physician.”⁴⁸ There is no mention of a prognosis of death within six months or any other specific period, nor has DHMH adopted such a prerequisite by regulation. The pertinent regulation, for Medicaid managed care, simply requires that each managed care organization “include in its benefits package medically necessary and appropriate hospice care services to enrollees who are terminally ill.”⁴⁹

Similarly, private health insurers are required by Maryland law to “offer benefits for hospice care services” to their insureds.⁵⁰ The law does not define hospice care in this context, so a private insurer could provide a hospice benefit that covered palliative care intertwined with curative efforts, well before any definitive terminal prognosis. Nevertheless, the Medicare construct for defining a terminal illness has permeated the field, so that public and private insurers and providers routinely equate hospice eligibility with a six-month prognosis for death. Hence, reform in Medicare is a key to reform in other settings.

Public Education

A coordinated public education agenda on end-of-life cancer care should address the lack of knowledge and the misconceptions that exist in understanding the end-stage disease process, the choices of treatment options, advanced care planning, and the services that are available for end-of-life care.⁵¹ Public education should be the responsibility of the patient’s health care providers, interdisciplinary specialists in end-of-life care, and state health officials. Educational efforts need to be directed at not only those who have end-stage cancer, but their caregivers and the networks of community systems impacted by the illness, including workplaces, schools, places of worship, and social support services. It is important to note the cultural, religious, and personal biases towards end-of-life care that can influence both health care providers and the public when planning educational initiatives.⁵²

The general public should be able to understand the full realm of treatment options for advanced cancer, the possible benefits and burdens associated with each option, and the common physical, psychosocial, and spiritual concerns associated with end-stage disease. Learning effective coping strategies for relieving pain and suffering should be a primary goal in any cancer care program that values comfort.

Although Maryland has made great strides in advanced care planning, educators need to be particularly adept and sensitive to religious, ethical, and legal implications when facilitating decision-making related to resuscitative measures, artificial hydration and nutrition, and pain control. It is best to address these issues as well as the process for surrogate decision-making prior to crisis situations in order to give patients and caregivers adequate time to thoughtfully consider their options.

In planning for end-of-life care, Marylanders should be able to identify the full realm of services available to them, including palliative and hospice care and any bereavement services that are offered to caregivers. Additionally, they should understand how services may be coordinated in a hospital, in a hospice residence, at home, at a nursing home, or in an assisted-living facility. Studies have shown that most Americans are unaware of their care options at the end of life and are usually referred to palliative care and hospice programs very late in their disease process. The length of stay in hospice programs has gradually decreased since the inception of the Medicare hospice benefit over twenty years ago. Unfortunately, most patients and families have been

unable to fully benefit from comprehensive supportive services. Thus the public would benefit greatly from end-of-life educational resources made available in a wide variety of settings.

The public deserves a coordinated and comprehensive effort that fully engages health care providers, the end-of-life care professional community, and state officials in addressing these many educational needs. All Marylanders must be given the opportunity to receive high quality and timely end-of-life care.

Provider Education

Improving the quality of end-of-life care for cancer patients will require improved awareness, knowledge, and skills of the health professionals who provide their care. These include symptom management, application and limits of life-prolonging interventions, prognostication and recognizing dying, conveying difficult news, providing information and guidance on prognosis and options, sensitivity to religious, ethnic, and other differences, and understanding palliative and hospice services.

Deficits in end-of-life care education, knowledge, and practice among health care professionals have been well documented. The Institute of Medicine report, "Improving Care at the End of Life,"⁵³ notes three major deficiencies:

- "A curriculum in which death is conspicuous mainly by its relative absence."
- Educational materials that are notable for their inattention to the end stages of most diseases and their neglect of palliative strategies.
- Clinical experiences for students and residents that largely ignore dying patients and those close to them."

A recent survey of pediatric oncologists regarding end-of-life care revealed a high reliance on trial and error in learning to care for a dying child, pointing to the ongoing need for education and strong role models.⁵⁴ The American Society of Clinical Oncology has developed a policy for improving end-of-life cancer care⁵⁵ and the National Comprehensive Cancer Network (NCCN), of which The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins is a member, has developed palliative care guidelines.⁵⁶ These and other resources are available, but these programs are not widely used in Maryland. Educational curricula and supports have been developed for a variety of groups, such as medical stu-

dents,⁵⁷ internal medicine residents,⁵⁸ nurses,⁵⁹ and social workers, and end-of-life education is now available in many training programs. Maryland programs should be encouraged to share and use these materials and curricula and to participate both in the development of new programs, such as for oncology fellows, and in research to improve the effectiveness of existing programs.

A survey of best-selling medical textbooks found that the oncology and hematology textbooks were in the quartile of specialties with the least end-of-life content. Follow-up research has shown that two of the six editors of the oncology/hematology textbooks, and many editors of other textbooks, report that they plan or have completed expansion of end-of-life content in these textbooks for future editions.⁶⁰ Maryland health professional training programs should be encouraged to use textbooks that have responded to this initiative and include adequate information on end-of-life care.

In order to truly improve care for terminally ill cancer patients, end-of-life care should not be marginalized in special courses or a single visit to a hospice program but integrated throughout curricula and clinical practice. In addition, resources and support should be available to expand the number of professionals with advanced training in end-of-life care to serve as teachers, consultants, and role models, and hospice professionals should be incorporated into Maryland training programs.

End-of-Life Research

This chapter has explained how the care of terminally ill cancer patients in Maryland may be improved by enhancing access to health services, reworking reimbursement, engaging the public, and educating providers. Implementing these important initiatives will be much more successful if accompanied by high-quality, targeted research. Improving health services and access will require knowledge of the main barriers to quality end-of-life care faced by Maryland residents with cancer. Improving clinical practice will require assessments of quality of care deficits and their impact on patients' quality of life. Engaging the public will be more effective with information on why end-of-life care is important. Quality improvement programs will be more effective and disseminated more widely when careful evaluations have demonstrated efficacy.

An active research agenda including data collection is a critical part of the effort to improve end-of-life care for Maryland citizens. Improved and uniform data collec-

tion throughout the state, in collaboration with the Hospice Network of Maryland and local cancer centers, is one method for evaluating existing end-of-life services. The collection of such data will make it possible to document barriers and gaps in care. Once this type of framework is available, further research regarding access, satisfaction, and other outcomes will be possible. Funding agencies may begin to consider investing in end-of-life care initiatives at the encouragement of the consumer and when initiatives are evidence-based. Providing opportunities and incentives for collaboration will allow end-of-life research to become better incorporated into our outstanding cancer centers and assist in recruiting world-class experts in end-of-life care and research to Maryland.

Data from the *Dartmouth Atlas*⁶¹ and the Last Acts Report on Dying in America Today⁶² compares end-of-life care in Maryland to that delivered in other states. This data is retrospective in nature and applies only to the very end-of-life rather than patients living for years with a chronic cancer. These reports are derived from population and health care delivery data and they do not address the clinical concerns of patients. Real improvement in end-of-life care in Maryland would benefit from:

- developing current data sources, such as the Maryland Discharge Database.
- promoting collaboration between hospices, which often have their own databases, for research purposes.
- encouraging inclusion of end-of-life care issues in longitudinal studies of cancer patients in clinical trials.
- reviews of medical records to determine quality deficiencies.
- systematic surveys of patients, families, and providers to identify barriers they faced in obtaining quality care at the end of life.
- better epidemiological statistics related to death rather than only support care geared to prolonging survival.
- cost analyses of end-of-life care in a variety of settings and via various funding mechanisms.

Important information that could be obtained from improved data sources or targeted research projects might include:

- longitudinal experience of patients dying from cancer.

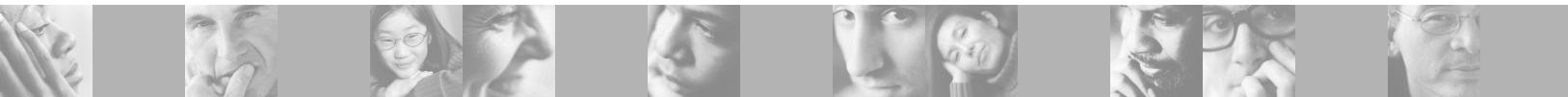
- how, when, and where patients die.
- quality of end-of-life care among hospices, nursing homes, hospitals, and characteristics associated with improving quality care.
- symptom prevalence and degree of symptom control obtained.
- barriers encountered by Maryland cancer patients searching for quality end-of-life care, including hospice and nursing home issues.
- novel service delivery models with potential for dissemination.
- successful quality improvement programs.
- successful partnerships that improve end-of-life care.
- disparities in access, preferences, and quality of end-of-life care.
- staffing needs for proposed improvements in health services at the end of life.

Maryland residents are fortunate to have many providers contributing to end-of-life care, but there is an increasing need for partnerships to improve the effectiveness of research in end-of-life cancer care. Since terminally ill cancer patients may often use multiple sources of care, including hospitals, private physicians, nursing homes, and hospice, integrated data may be necessary to provide an accurate picture of patients' longitudinal experiences. And although Maryland has many small hospice programs, an organizing framework already exists through the Maryland Hospice Network. Potentially, this could be expanded to include collaborative data collection that would provide a more complete picture of hospice and palliative care in Maryland. Furthermore, since few providers or researchers specialize in end-of-life care, collaboration between the University of Maryland, Johns Hopkins University, and any other interested research entities would also greatly enhance the quality of research initiatives.

Ensuring that Maryland's investments in such programs are worthwhile and determining whether to disseminate small pilot programs to larger populations or other health systems will require careful evaluations. Proposed initiatives that might benefit from accompanying program evaluation include waiver programs for hospice, hospice collaboration to provide care to complex patients, longitudinal palliative care programs, home caregiving programs, public education, and provider education.

Improving the quality of end-of-life care, and of the research evidence in this area, will require incorporation of end-of-life issues into other cancer research. To better describe and provide care during the current chronic trajectory that many cancer patients experience, it will be necessary to integrate palliative and supportive efforts long before patients are within days to hours of dying. Integration will indicate factors that might be helpful in predicting prognosis. For example, advance care planning may be beneficial after diagnosis and after treatment has begun, when the patient feels less anxious. This approach may or may not be more effective coming from a neutral health worker rather than the physician. End-of-life issues, such as the control of pain and fatigue, occur throughout the cancer trajectory. Studies that focus solely on the end of life may be jeopardized by high mortality and difficult data collection; incorporating this research into longitudinal cancer studies and clinical trials may greatly improve its effectiveness.

Research into issues faced by terminally ill cancer patients would benefit from incorporating these issues into other cancer funding initiatives. Symptom management, documenting quality of life, and measurement of patient and family satisfaction with the type of care received should all be incorporated into funding initiatives from the Maryland Cigarette Restitution Fund. Experts on end-of-life care should be included on committees approving these expenditures to ensure that issues faced by terminally ill persons are included in proposals where appropriate. An evaluation component must be written into every study to ensure that results are meaningful and useful for dissemination.



End-of-Life Care Goals, Objectives, and Strategies

Goal:

Increase the number of Maryland cancer patients, as well as their family members and friends, receiving quality end-of-life care and related services.

Target for Change

By 2008, develop a system to monitor the availability and quality of end-of-life care services for cancer patients in Maryland, with specific attention to the needs of special populations including pediatrics and minorities.

Objective 1:

Expand provider education and training related to end-of-life care.

Strategies:

1. Require end-of-life education as part of core curriculum for *all* health care providers in training. Content areas should include, but not be limited to: aggressive symptom management; application and limits of life-prolonging interventions; prognostication, communications and conflict resolution; providing information and guidance on prognosis, options, and decision-making; sensitivity to cultural, religious, and other differences; understanding palliative and hospice services; understanding grief and loss issues; and sensitivity to the psychosocial and spiritual needs of patients and their family members and caregivers.
2. Require specialized end-of-life education for providers that care specifically for cancer patients (e.g., oncologists, primary care providers, social workers, chaplains, etc.) and specialized training for providers caring for pediatric oncology patients, recognizing the unique needs of children and their families at the end of life.
3. Promote membership in and support of organizations that work to improve end-of-life care.
4. Support organizations engaged in proactive outreach including end-of-life training of health care and insurance providers.

**Objective 2:**

Increase public awareness of end-of-life issues.

Strategies:

1. Support organizations engaged in proactive outreach including community education and political advocacy on end-of-life issues.
2. Increase public awareness of existing end-of-life educational resources such as websites and hotlines.
3. Provide community based end-of-life education for minorities and underserved populations, including multilingual education campaigns and outreach.
4. Provide comprehensive end-of-life care educational resources in all oncology clinics, cancer centers, nursing homes, and assisted-living facilities, and make this information readily available on corresponding websites.

Objective 3:

Improve access to end-of-life care for all Marylanders with specific attention to improving physician reimbursement for appropriate end-of-life care.

Strategies:

1.
 - Identify existing information about the end-of-life care needs of populations including pediatric, adult, and geriatric patients and special needs groups such as the developmentally disabled and minority populations. Develop additional data as needed to prepare a comprehensive needs assessment for these populations.
 - Develop and implement strategies to meet the needs identified in the above assessment.
2. Encourage the Centers for Medicare and Medicaid Services to implement pilot programs, with careful attention to the collection of data on both cost and patient satisfaction, that would reimburse providers for a full range of palliative care services for patients with any type of cancer that frequently results in

death, with no requirement that life expectancy be six months or less. The benefit should be available whether or not a patient continues to pursue therapies aimed at remission or cure.

3. Encourage the Maryland Medicaid program to contract with managed care organizations to implement pilot programs, with careful attention to the collection of data on both cost and patient satisfaction, that would reimburse providers for a full range of palliative care services for patients with any type of cancer that frequently results in death, with no requirement that life expectancy be six months or less. The benefit should be available whether or not a patient continues to pursue therapies aimed at remission or cure.
4. Encourage the Maryland Insurance Commissioner to study industry compliance with Section 15-809 of the Insurance Article, which requires insurers and nonprofit health service plans to offer benefits for hospice care services, and take appropriate steps to remedy any noncompliance.
5. Support the development of tax credits for informal caregivers, such as family members and spouses, in an effort to alleviate the devastating financial burden of providing end-of-life care.
6. Increase provider reimbursement for the longer evaluations and more extensive management required for terminally ill patients. In addition, adequately reimburse health care professionals for time spent discussing advance care planning with patients.

**Objective 4:**

Enhance access to the continuum of end-of-life care services throughout the state.

Strategies:

1. Enhance existing partnerships and create new ones among hospices and facilities such as hospitals, home care agencies, nursing homes, and assisted living facilities caring for patients with cancer and other terminal illnesses.
2. Promote the creation of palliative care teams in acute care settings.
3. Support the use of care managers to serve as a constant as patients and their families move among different care settings from diagnosis to bereavement.
4. Support the development of, and reimbursement for, prehospice or bridge programs which offer some of the services of hospice with less stringent eligibility requirements.
5. Support and provide funding for the development of new inpatient and residential hospice facilities.

Objective 5:

Enhance scientific research into all aspects of end-of-life care.

Strategies:

1. Support and develop funding mechanisms for end-of-life research. Recognize and promote the importance of research, even with vulnerable populations, to better understand difficulties experienced by cancer patients throughout the trajectory of illness.
2. Develop a statewide mechanism for coordination and dissemination of interdisciplinary end-of-life research among various professional schools, professional organizations, and government agencies.
3. Support use of Cigarette Restitution Funds for end-of-life research and programs.

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