

Center to Reduce Cancer
Health Disparities (CRCHD)

Economic Costs of Cancer Health Disparities

SUMMARY OF MEETING PROCEEDINGS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health

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TABLE OF CONTENTS

FOREWORD	6
EXECUTIVE SUMMARY	8
SECTION 1 INTRODUCTION	
1.1 Background	11
1.2 Objectives	12
1.3 Think Tank Process	12
1.4 Organization of Report	12
SECTION 2: OVERVIEW	
2.1 Definition of Disparity	13
2.2 Determinants of Disparities	14
Factors Within the Health Care Delivery System	14
Factors External to the Health Care Delivery System	15
2.3 Screening, Diagnosis, and Treatment Disparities: the Cancer Care Continuum	18
SECTION 3: TOTAL COST OF CANCER CARE	
3.1 Overview of Cost Domains	20
3.2 Overall Cost of Cancer Care	21
Direct Health Care Costs	22
Time Costs	23
Employment Costs	23
3.3 Data Limitations	24
SECTION 4: ECONOMIC BENEFITS OF REDUCING CANCER HEALTH DISPARITIES	
4.1 Benefits of Reducing Cancer Health Disparities	27
4.2 Measuring the Value of Reducing Disparities	28
Estimating Mortality, Morbidity, and HRQL Impacts	28
Estimating Economic Impacts	29
SECTION 5: BENEFITS AND COSTS OF POLICIES TO REDUCE CANCER HEALTH DISPARITIES	
5.1 Why Economics Matter	33
Comparing Cost and Effectiveness	33
Budget Impact Analysis	34
5.2 Importance of Perspective in Economic Assessment	34
5.3 Calculating Incremental Cost-Effectiveness Ratio	35
5.4 Characteristics of Potentially Cost-Effective Interventions	35
5.5 Provider Incentives and Barriers to Change	35
SECTION 6: RECOMMENDATIONS AND RESEARCH AGENDA	
6.1 Research Recommendations	37
6.2 Policy Recommendations	38
REFERENCES	41
GLOSSARY	46
APPENDIX A: PARTICIPANT LIST	48
APPENDIX B: ECONOMIC COSTS — DISCUSSION QUESTIONS	52
APPENDIX C: ECONOMIC COSTS — BACKGROUND PAPER	54
APPENDIX D: AGENDA AND MEETING PRESENTATIONS	70

LIST OF FIGURES

Figure 1: Ratio of the Probability of Diagnosis of Cancer at Late Stage, Uninsured Compared with Insured, 1994. 14

Figure 2: Causes of Cancer Health Disparities. 15

Figure 3: U.S. Cervical Cancer Mortality by Race and Poverty Level, 1996-2000 16

Figure 4: Critical Disconnect Between Research/Discovery and Delivery of Care 17

Figure 5: Cancer Care Continuum 17

Figure 6: Treatment Cost and Survival: Breast Cancer 21

Figure 7: Framework for Assessing Economic Costs of Cancer Health Disparities 27

Figure 8: Cost Effectiveness Plane 33

Appendix Figure C-1: Causes of Health Disparities 56

Appendix Figure C-2: The Cancer Care Continuum 58

Appendix Figure C-3: Types of Health Care Costs 62

LIST OF TABLES

Table 1: Specific Cost Elements Required for Measuring Total Cost of Cancer Care 20

Table 2: Cancer-Related Treatment Cost of Colorectal Cancer. 22

Table 3: Estimates of Direct Costs for Cancer Based on SEER Medicare Data, 1996 22

Table 4: Time Costs Related to Colorectal Cancer Treatment: Difference in Cost for Cases Versus Controls (Net Costs). 22

Table 5: Comparison of CEA, CBA and CUA 34

Foreword

Why examine the cost of cancer health disparities? Disparities in cancer care and outcomes result in both economic and human costs. Public policy approaches to eliminate cancer-related disparities require an understanding of these costs to find appropriate balances between the actual dollars spent and the potential value to American society. For these reasons, understanding the costs associated with these disparities is vital to the work of the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities. This first NCI Think Tank on the economic costs of cancer health disparities was an important step in exploring these issues.

Considerations of the cost of cancer health disparities often focus principally on the expenditures associated with eliminating existing disparities. However, current disparities have an ongoing cost that is less well recognized. Specifically, all people with cancer in America eventually receive care, since severely symptomatic patients seldom are denied hospital care. But if treatment is ineffective because the disease already is advanced, the associated costs likely will be higher both in dollars and in human suffering.

The Think Tank participants emphasized the distinction that must be made between cost and value. They further underscored that both cancer disparity costs and the value accruing from reducing these disparities may be tangible and intangible. For example, tangible costs may include dollars spent on treatment and lost wages, whereas tangible value may include reduced individual and health system costs, lives saved, and restored productivity. Intangible costs of cancer may include emotional anguish and diminished quality of life for patients and their families, whereas intangible value may include reduced suffering and the opportunity to redirect health care resources to disease prevention.

Disparities specific to cancer may be among the more easily measured types of health disparities because of existing cancer-specific data collection infrastructure. Even so, based on the limited studies to date using these data, we cannot yet quantify the full costs of existing cancer disparities, the cost of eliminating these disparities, or the real and perceived value of eliminating them. Nor can we assess, except at a philosophical level, whether the value is worth the cost.

Moreover, perceptions of cost and value may vary according to different cultural and societal norms. Cancer health disparities differ by disease, by population, by geographic region, by age, by gender, and by other parameters. Therefore, the economic costs of cancer health disparities must be assessed from many perspectives, including those of society in general, government, population groups, employers, insurers, and each affected individual.

The fundamental question centers on the cost-benefit that could be realized over time compared with the current economic and human costs of cancer health disparities. Exploring this and other related crucial questions illuminated the current gaps in knowledge that must be filled to appropriately frame and address the issues. It was clear from the Think Tank deliberations that no consensus currently exists on how to measure or balance the costs and benefits to the nation of eliminating cancer health disparities.

Most Americans would agree that in the aggregate, we have made great advances in this nation with respect to disease in general, as reflected by the remarkable increases in average life span and quality of life since 1900. But some groups of people have not enjoyed these benefits as much as others, as evidenced by their outcomes of cancer and other diseases. Many people, regardless of economic status, education, and insurance coverage, have great difficulty negotiating the health care system and getting from the point of an abnormal finding and a cancer diagnosis through the treatment of their disease.

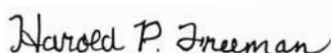
This problem, often resulting in reduced survival, inflicts the greatest burden on the poor, who typically lack fiscal, educational, and information resources.

A cascade of problems—such as financial and geographic barriers to treatment; ineffective provider-patient communication; inadequate screening, and insufficient post-treatment and long-term follow-up—can occur in varying combinations over time, resulting in increased cancer-related costs. We do not fully understand all of the potential interrelationships of these problems, but our knowledge of them has improved. One thing has become clear: social injustice leading to unfair inequities is at the core of most of these problems.

Realistically, we know that disparities will always exist at some level, because our social and health care systems cannot be corrected such that every person will have equal access to care, comparable living conditions, and equal amounts of resources. Nonetheless, we suggest that we can dramatically minimize disparities and their costs by agreeing as a society, and committing to the belief, that it is unacceptable for any person with cancer to go untreated. Further, we must ensure that any inequities in care are not caused or exacerbated by biases related to race, ethnicity, culture, or socioeconomic status.

The participants in this Think Tank were drawn from diverse disciplines, including health care delivery, health economics, health policy, statistics, health services research, public health, and social science research. They were charged to consider the underpinnings of this complex problem and offer suggestions for better understanding and addressing these issues. Their deliberations provided the basis of the recommendations in this report.

Cancer health disparities are not only an economic and medical concern but also an extraordinary moral and ethical dilemma for this nation. We hope that the considerations and recommendations contained in this report will be a tool to stimulate vigorous discussion and bold action to address these issues.



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Executive Summary

There is a significant disconnect between the development of efficacious prevention and treatment options established through cancer research and the delivery of this care to all population groups, most notably cancer patients from certain racial and ethnic minority groups, individuals with low socioeconomic status, residents in certain geographic locations, and individuals from other medically underserved groups.¹ Improving the delivery of cancer care to these population subgroups may help to reduce cancer health disparities in the United States.

There are several different definitions of disparities and the conclusions regarding the impact of disparities can differ based on the definition used.² The NCI's definition of cancer health disparities is as follows:

“Disparities, or inequalities, occur when members of some population groups do not enjoy the same health status as other groups.

Disparities are determined and measured by three health statistics: incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another.

Disparities are most often identified along racial and ethnic lines, i.e., African Americans, Hispanics, Native Americans/Alaska Natives, Asian Americans/Pacific Islanders, and whites have different disease rates and survival rates. However, factors contributing to disparities extend beyond race and ethnicity. For example, cancer health disparities can also involve biological, environmental, and behavioral factors, as well as differences on the basis of income and education.”³

Disparities in care exist along the entire cancer care continuum—from primary prevention, to screening and diagnosis, to treatment and follow-up services. Examining and understanding the economic and human costs of cancer health disparities to patients, families, employers, providers, and society as a whole may be helpful in developing strategies to eliminate or reduce such disparities. There could be significant benefits to eliminating these disparities, including a reduction in mortality, decreases in cancer- and treatment-related morbidity, and improved quality of life. Measurement of these human benefits can be captured in part through estimates of quality-adjusted life years (QALYs), which are composite measures that include improvements in the length of life and in the quality of life associated with a particular health-care intervention. The overall economic value to society of reducing disparities can be assessed through cost-effectiveness analyses and cost-of-illness and/or value-of-health studies. Components of these studies may include the direct medical and non-medical costs (related to provision of health services), indirect costs (e.g., time lost from work and other economic activities), and concurrent changes in population mortality and morbidity.

The costs related to cancer health disparities have not been systematically and comprehensively assessed to date. To address this critical need, the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI) convened a Think Tank meeting on December 6–7, 2004. The Think Tank meeting was convened upon recommendation of an ad-hoc group of experts that met prior to this meeting. The meeting consisted of individual presentations from an interdisciplinary team of experts, as well as group discussions and breakout sessions to explore identified issues in greater depth. The key areas of discussion were the total costs of providing cancer care including a critical assessment of the data limitations, challenges in measuring the value of reducing cancer health disparities, and the importance of measuring the cost-effectiveness of interventions to reduce cancer health disparities. At the conclusion of the two-day meeting the participants provided a list of recommendations and future research activities. This report synthesizes the presentations and discussions of the Think Tank.

Several key conclusions were reached by the Think Tank participants. First, existing data sources have not been used adequately to explore issues related to cancer health disparities and there are no population-level data sources available currently to systematically estimate patient-level costs of these disparities. Improvements in the available data sources may allow for the estimation of overall patient-level cost burdens related to disparities. The data sources can be improved in several ways: by increasing the sample of minority populations (e.g., African Americans, Native Americans/Alaskan Natives; Asian Americans/Pacific Islanders) available for analysis; by developing a national database on cancer epidemiology, outcomes and resource use; by performing linkages among currently available databases and by clearly understanding and adopting national standards (e.g., Office of Management and Budget [OMB] Directive 15)⁴ on race/ethnicity coding. In addition, decision analytic models can be used to combine effectiveness and cost information from these various data sources to estimate the cost of cancer health disparities. Second, there are significant overlapping determinants of disparity and therefore there is considerable challenge in identifying the cost impact of specific determinants. As cancer health disparities are not just an issue

among racial minority groups, the association between factors such as low socioeconomic status (SES) and cancer health disparities should also be examined (although African Americans have the highest rate of poverty, about 25%, the majority of Americans below the federal poverty level are white).⁵ Third, since resources available for health care and other services are finite, economic evaluations are essential to identify interventions that are cost effective. Interventions that are likely to be cost effective are those that address target populations with high degree of disparities, those interventions that are highly effective, and those that are low cost.

Through breakout group discussions, the participants addressed the economic consequences and costs of cancer health disparities and made numerous recommendations of cost-effective interventions for eliminating these disparities. The recommendations are summarized below in two subsections—research and policy.

Research Recommendations

1. Focus on cancers with modifiable attributes and fund prospective clinical trials to evaluate primary prevention strategies;
2. Study processes to develop improved data sources that will facilitate collection and analysis of cost and outcomes data;
3. Develop better methods and tools to measure disparities;
4. Assess geographic variation and other factors that result in disparities;
5. Include cost-effectiveness assessments in clinical trials and other intervention studies that address disparities;
6. Identify changes in the health care delivery system that can reduce the economic burden of cancer health disparities; and,
7. Initiate studies to quantify uncompensated cancer care.

Policy Recommendations

1. Improve and expand current insurance coverage;
2. Sponsor health policy research to assess impact of cancer payments on quality of care;
3. Reduce geographic differences through community-level interventions;
4. Eliminate health care network disconnects; and
5. Promote primary prevention for cancer sites where evidence supporting primary prevention exists (e.g., HPV vaccine).

The research topics and recommendations identified by the Think Tank participants will help direct NCI's efforts in quantifying the economic burden of cancer health disparities and inform policies to eliminate cancer health disparities. A number of specific next steps were identified. First, convene a panel of experts to identify a detailed process for improving both the epidemiological and cost data available to study and assess measures to reduce cancer health disparities. Second, sponsor studies to develop better methods to measure cancer health disparities and to evaluate the costs associated with cancer health disparities. Third, include cost-effectiveness assessments in any clinical trials or interventions sponsored by NCI to reduce cancer health disparities. Fourth, coordinate activities with other federal agencies, including Centers for Medicare and Medicaid Services (CMS), to implement initiatives to reduce cancer health disparities.



Introduction

SECTION 1

1.1 Background

There is a significant disconnect between cancer research *discovery/development* (i.e., what we know) and the *delivery* of care to cancer patients (i.e., what we do).⁶ This disconnect is an important factor contributing to an imbalanced and unjust burden of cancer in our society—the burden falling on some racial and ethnic minority groups, individuals with low socioeconomic status (SES), residents in certain geographic locations, and other medically underserved groups. Improving the delivery of cancer care to these population groups would help to reduce cancer health disparities in the United States.

Examining and understanding the economic and human costs of cancer health disparities is an important step in eliminating such disparities. Understanding the economic costs and human costs of cancer health disparities may provide guidance to policy makers with regard to cancer health care. To address this need, the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI) convened a Think Tank meeting on December 6–7, 2004. This meeting brought together health economists, cancer care providers, insurers, and policy experts to explore the economic costs to the nation resulting from cancer health disparities among certain population groups (including racial and ethnic minority groups and individuals with low SES) and to identify potential interventions to address these disparities. The purpose of this report is to provide a summary of the ideas and discussions that occurred during this meeting and to review the current knowledge on the economics of cancer health disparities.

1.2 Objectives

The original objectives of the meeting were:

- To examine the current evidence regarding the costs of cancer health disparities;
- To assess the currently available cost data and data needs related to costs of cancer health disparities;
- To explore new and creative ways of examining and estimating the economic costs of cancer health disparities (since there are currently not enough databases containing data of this nature);
- To strengthen the economic evidence base regarding the cost of cancer health disparities; and,
- To explore new and creative strategies for reducing and eventually eliminating cancer health disparities.

During the initial discussions among Think Tank participants, it became clear to the participants that the evidence to support the completion of the objectives listed above was not available; therefore, the participants focused on intervention strategies and future research areas which will enable completion of these objectives.

1.3 Think Tank Process

The Think Tank meeting consisted of individual presentations from the interdisciplinary team of experts, as well as group discussions and breakout sessions to explore certain issues in greater depth (see **Appendix A** for a list of meeting participants). Participants for the meeting were selected based on their expertise in specific areas of relevance to the Think Tank discussions, including clinical epidemiology, health care policy, and cost-effectiveness analyses. Prior to the meeting, all participants received a package of pre-planning documents, including a copy of the notes from the planning meeting convened by CRCHD (**Appendix B**) and a background paper on economic costs of cancer health disparities prepared by the CRCHD staff (**Appendix C**).

The two-day meeting began with introductions and discussions regarding the purpose and rationale behind convening this Think Tank meeting and the core questions to be discussed and answered. The agenda for Day 1 of the meeting consisted of six individual presentations followed by group discussion (The agenda and brief descriptions of the presentations are provided in **Appendix D**). Additionally, the six individual presenters participated in a panel discussion, during which both participants and observers asked questions and discussed the major issues from the day-long session. Day 2 began with a breakout session where participants were divided into two groups and given the same set of key questions:

- What is the total cost of cancer care?
- What proportion of the total cost of cancer care is related to health disparities?
- What would be the cost of eliminating cancer health disparities in America?
- What is the value of reducing cancer health disparities in America?
- What are the policy implications of reducing cancer health disparities?
- What is the cost of changing policies?

Deliberations and discussions from the breakout session were summarized and followed by final discussions and wrap-up.

1.4 Organization of Report

This report begins with an overview of the determinants of cancer care disparity and a description of the “cancer care continuum” (Section 2). Section 3 discusses the total cost of cancer care and limitations of currently available data sources. Section 4 presents the methodological issues related to reducing cancer health disparities, followed by Section 5, a discussion of the costs and cost-effectiveness of implementing interventions to reduce cancer health disparities. Finally, Section 6 summarizes the Think Tank’s recommendations for future research and policy initiatives.



Overview

SECTION 2

2.1 Definition of Disparity

There are several different definitions of disparities and the conclusions regarding the impact of disparities can differ based on the definition used.² The NCI's definition of cancer health disparities is as follows:

“Disparities, or inequalities, occur when members of some population groups do not enjoy the same health status as other groups.

“Disparities are determined and measured by three health statistics: incidence (the number of new cancers), mortality (the number of cancer deaths), and survival rates (length of survival following diagnosis of cancer). Health disparities occur when one group of people has a higher incidence or mortality rate than another, or when survival rates are less for one group than another.”³

The Minority Health and Health Disparities Act of 2000 provides the following definition of “disparity population”:

“A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population. In addition, ... [the definition may include] populations for which

there is a considerable disparity in the quality, outcomes, cost, or use of health care services or access to, or satisfaction with such services as compared to the general population.”⁷

2.2 Determinants of Disparities

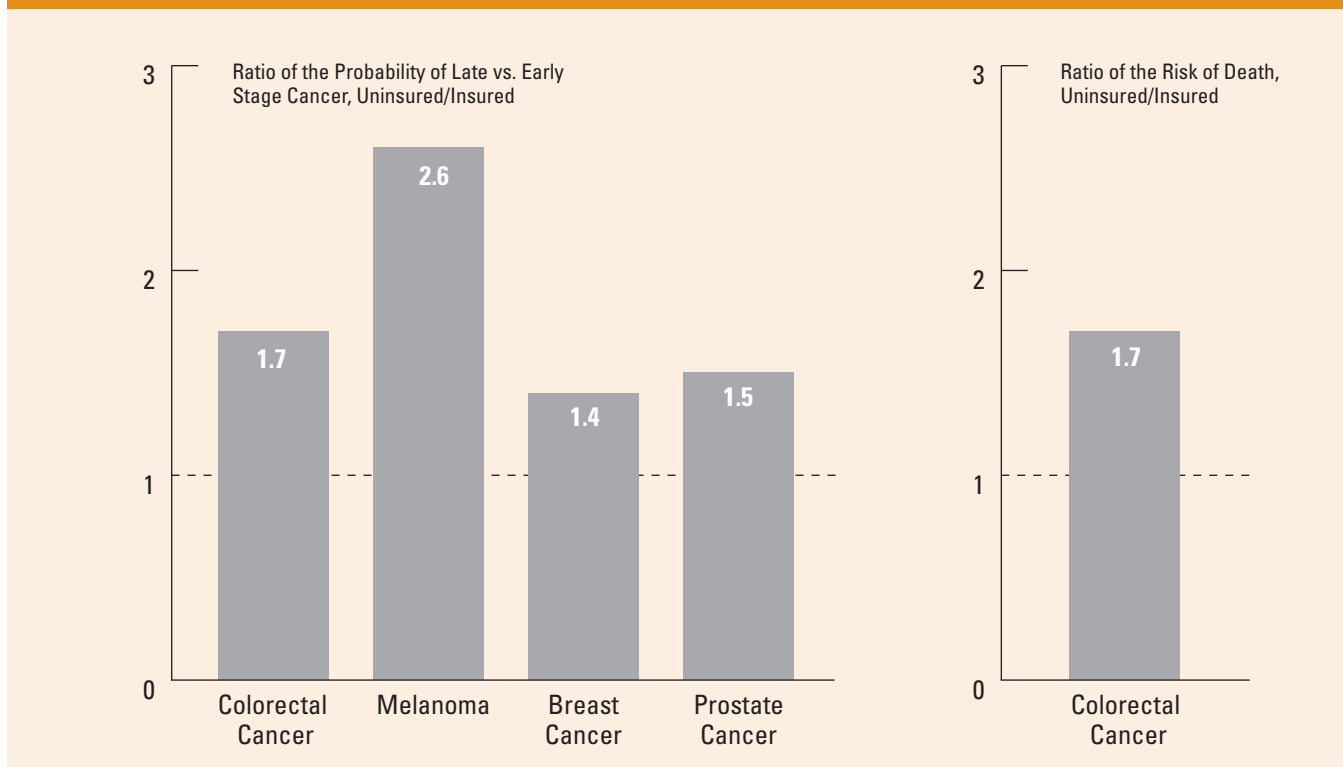
Determinants of cancer health disparities are underlying factors that may have an effect on individual outcome measures. Disparities are most often identified along racial and ethnic lines, i.e., African Americans, Hispanics, Native Americans/Alaska Natives, Asian Americans/Pacific Islanders, and whites have different disease rates and survival rates. However, factors contributing to disparities extend beyond race and ethnicity though.³ They include factors within the health care delivery system (e.g., access to health care, insurance coverage, health care network disconnects) as well as factors outside of the system (e.g., education, SES, geographic differences).

Factors Within the Health Care Delivery System

Within the health care delivery system, lack of insurance coverage is a major contributor to cancer health disparities. Furthermore, the stability and quality of insurance coverage is even more important than simply being insured. The U.S. Census Bureau reports that, in 2005, approximately 16% of the population (46.6 million people) had no health insurance coverage.⁵ The percentage of persons without health insurance was higher in certain racial groups and in groups with lower SES. Of Americans under 65 years of age who are diagnosed with cancer, 20% of Hispanics, 14% of African Americans, and 10% of whites do not have health insurance.⁸

An Institute of Medicine (IOM) report “Care Without Coverage: Too Little, Too Late,” found that uninsured patients with breast, colorectal, or prostate cancer are in poorer health and more likely to die prematurely than their insured counterparts, primarily due to delayed diagnosis.⁹ For example, an uninsured

FIGURE 1 Ratio of the Probability of Diagnosis of Cancer at Late Stage, Uninsured Compared with Insured,* 1994



* Privately insured all had commercial indemnity plans. ** Among cancer cases identified in 1994; mortality followup through 1997. All differences are statistically significant after adjusting for age, sex, race/ethnicity, co-morbidity, marital status (when appropriate), smoking status, socioeconomic status, education, stage at diagnosis, and treatment. SOURCES: The Kaiser Commission on Medicaid and the Uninsured, 2003.10

woman with breast cancer faces a 30%-50% higher risk of dying compared with her insured counterpart, and an uninsured person with colorectal cancer has a 50% greater chance of dying compared with someone who has private insurance.⁹ This finding is also true for other cancers, as shown in **Figure 1**.

Over time, high rates of persons without insurance coverage lead to unstable connections to care, disruptions in care, and greater costs. Lack of adequate insurance coverage limits access to care, partially due to cost-related issues¹² and partially due to the lack of a primary care provider.¹³ Finally, even in persons with low incomes who are insured, cost-sharing and out-of-pocket expenses compromise receipt of effective medical care.¹¹

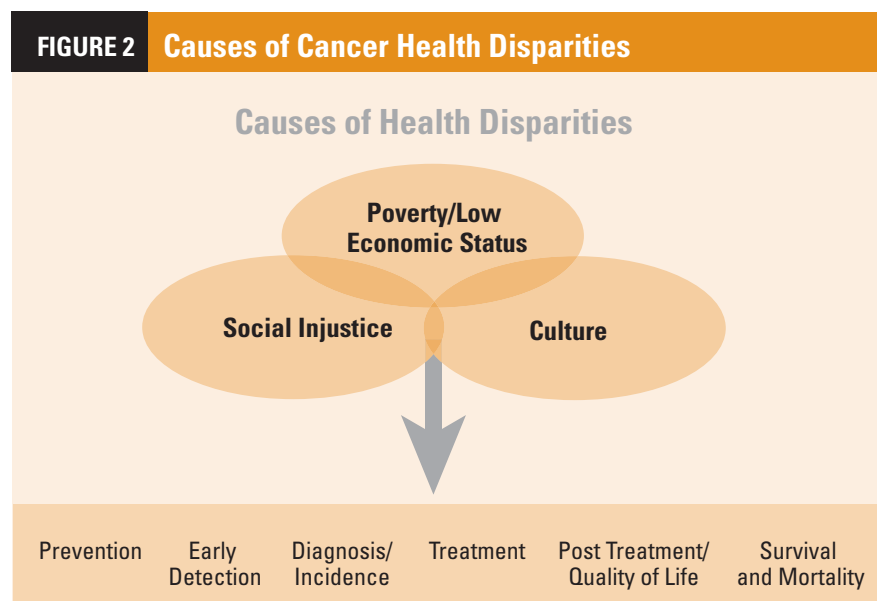
Factors such as availability of appropriate providers and services at an affordable cost and access to appropriate referral services are important to receiving high quality health care and, if compromised, can contribute to health care disparities. For instance, in rural areas there may be a lack of specialists which can lead to delays in diagnosis of cancer and treatment, or language barriers can result in non-English speakers not seeking or receiving appropriate care.⁹ Disruption of traditional community-based care can also lead to disparities as providers familiar with individuals in a particular locality may no longer be available.¹⁴

Factors External to the Health Care Delivery System

Factors external to the health care delivery system which contribute to disparities include gender, race, ethnicity, SES (income, education), and geographic location. According to Freeman (2004)¹, the three principal determinants of cancer disparities (**Figure 2**) are:

- Poverty (low SES);
- Culture; and
- Social Injustice.

Poverty is generally correlated with lack of information, risk-promoting behaviors, and reduced access to appropriate health care. The percentage of individuals living in poverty is disproportionately high among African Americans, Hispanics/Latinos, Native Americans, Pacific Islanders, and Native Hawaiians compared with white Americans. The poor are at greater risk of being diagnosed and treated for cancer at late stages of disease and are less likely to survive a diagnosis of cancer. Among the three main determinants, poverty contributes to health disparities more than the other two factors.¹ A study of colorectal cancer screening among Medicare beneficiaries concluded that much of the disparities in screening rates can be explained by differences in socioeconomic status. Disparities in socioeconomic status decreased but remained significant even after adjustment for personal and health system factors.¹⁵



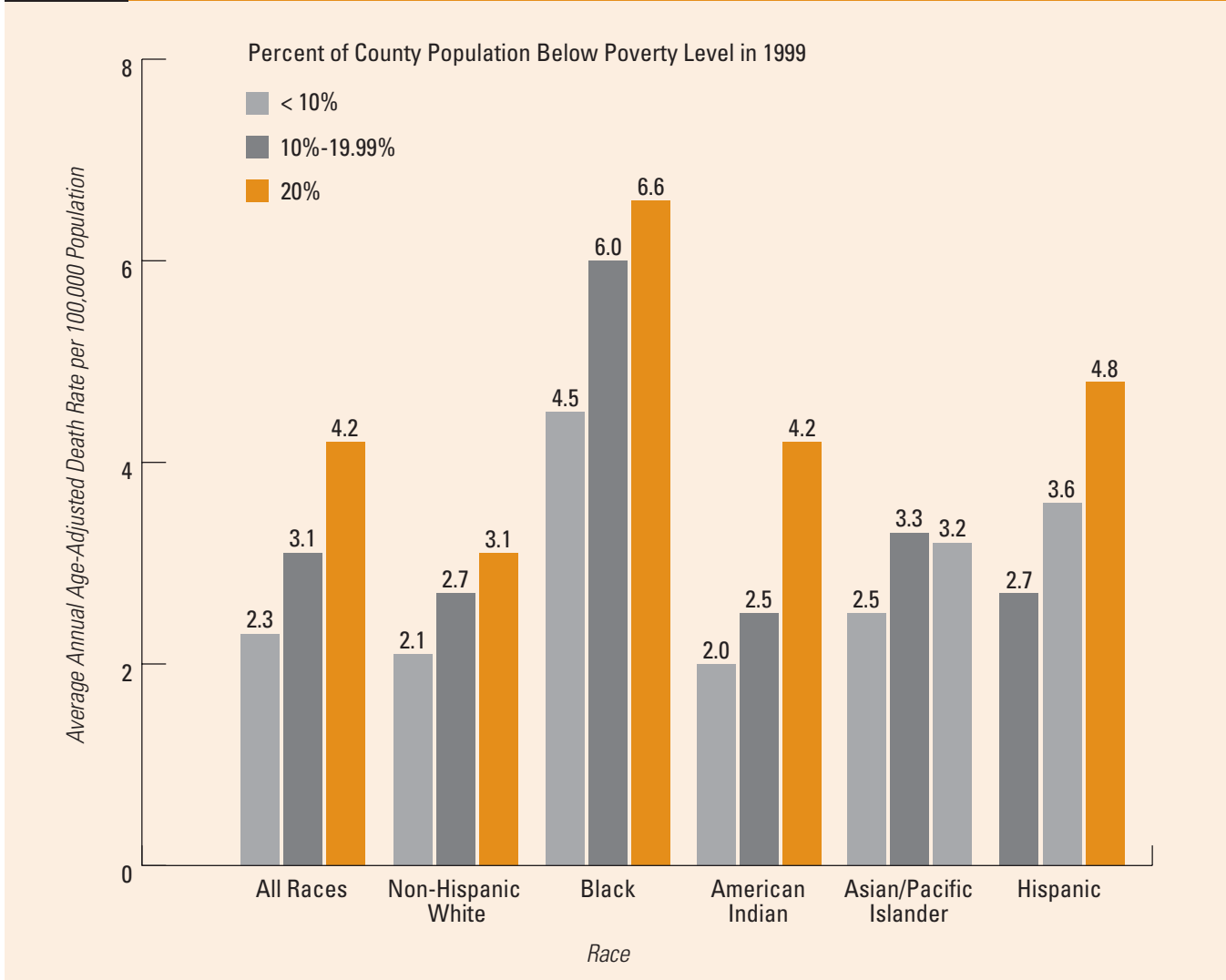
SOURCE: Freeman, Adapted from Cancer Epidemiology Biomarkers & Prevention, April 2003.

A recent report published by CRCHD on cervical cancer (2005) and research by Singh and colleagues¹⁶ highlights the correlation of SES and disparities in the incidence and mortality of cervical cancer at the county-level in the United States. The study found substantial inequalities in both the incidence and mortality of cervical cancer, with rates of disparities becoming higher with increasing poverty and decreasing education levels. Patients living in lower SES census tracts were also significantly more likely to be diagnosed at late stages of the disease and were less likely to survive. **Figure 3** highlights these disparities.

Although poverty is considered a primary determinant of cancer health disparities, much of the statistics on disparity are also related to racial differences. Race itself does play a role in determining cancer disparities.^{17, 18} A recent IOM report (2002) found that racial and ethnic disparities in health care exist in the context of broader-scale social and economic inequalities. The report concluded that these disparities persist even after controlling for SES (i.e. income and education). Selected statistics from the NCI and the National Center for Health Statistics (NCHS) indicate several racial disparities.¹⁹

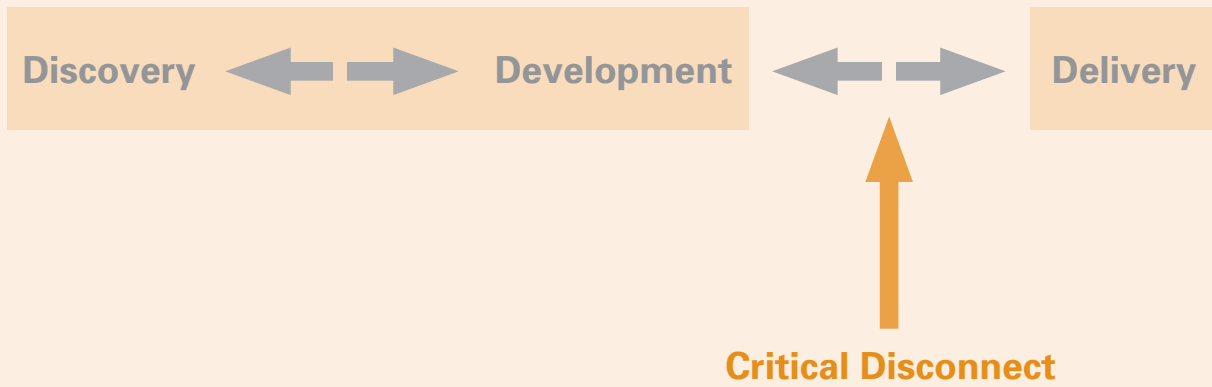
- African Americans have the highest cancer incidence and cancer-related death rates overall;
- African American males have the highest incidence and mortality rates for colon, prostate, and lung cancers;
- While Caucasian American females have the highest incidence of breast cancer, African American females have the highest death rates for breast cancer;

FIGURE 3 U.S. Cervical Cancer Mortality by Race and Poverty Level, 1996-2000



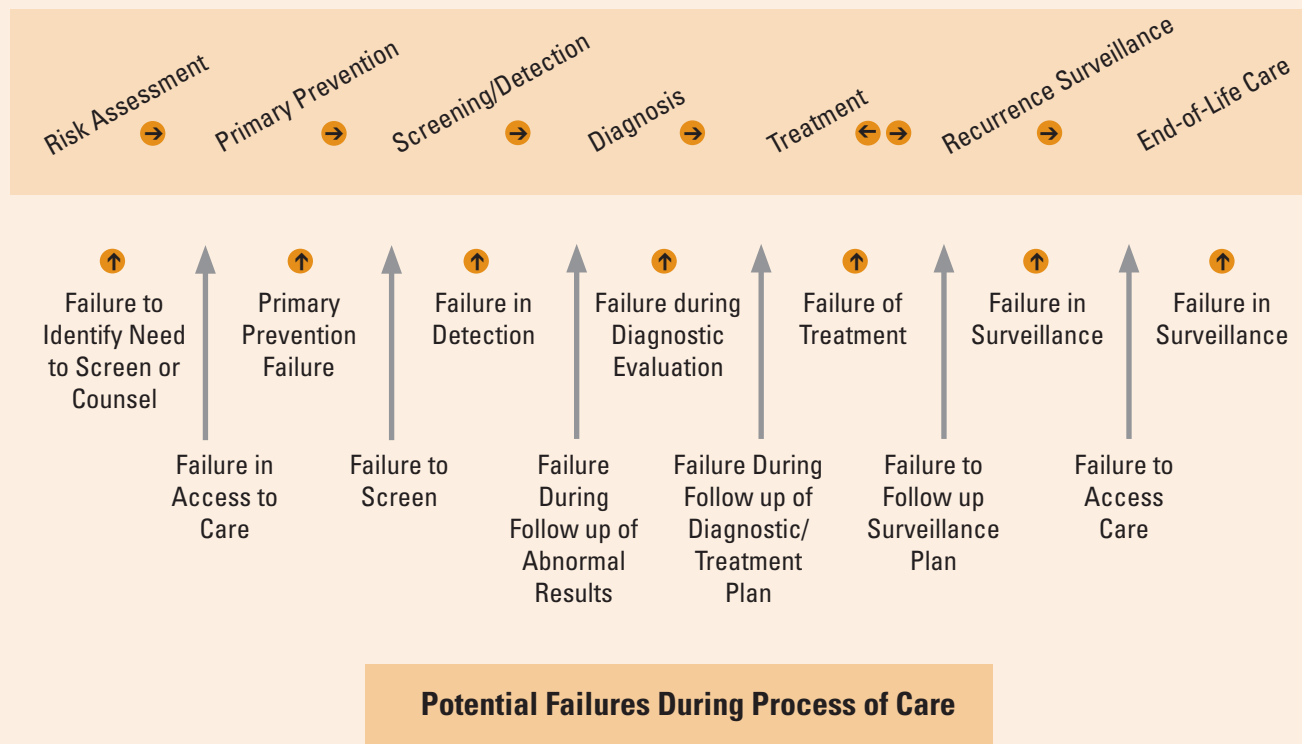
SOURCE: Singh et al., 2004.¹⁶

FIGURE 4 Critical Disconnect Between Research/Discovery and Delivery of Care



SOURCE: Freeman, 2000.⁶

FIGURE 5 Cancer Care Continuum



SOURCE: Zapka et al., 2003.²⁰

- Hispanic/Latina females have the highest incidence rates among all racial groups for cervical cancer, and Vietnamese females [a subset of Asian-Pacific Islanders] have the highest mortality rates among all racial groups for cervical cancer; and,
- Asian/Pacific Islanders have the highest incidence rates of liver and stomach cancers for both sexes.

2.3 Screening, Diagnosis, and Treatment Disparities: The Cancer Care Continuum

Freeman has hypothesized that there is a critical disconnect between cancer research *discovery/development* and the *delivery* of care to cancer patients⁶ as illustrated in *Figure 4*.

Even for those who have access to care, the Cancer Care Continuum (*Figure 5*) illustrates that disparities in cancer care can occur at any stage of screening, diagnosis, or treatment. In the continuum from risk assessment through end-of-life care, a patient can fail to receive adequate care during any or all steps of the process. For example, a patient may not be screened appropriately, may not receive adequate treatment, may not be able to access end-of-life care, or may experience all three as well as other failures during the process.

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