Determinants of Cancer Disparities: Barriers to Cancer Screening, Diagnosis, and Treatment

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In 1971, President Richard Nixon declared a war on cancer and signed the National Cancer Act. Since that time, there have been great research advances. In the subsequent years there have been declines in mortality overall and for some specific cancers, such as breast, colorectal, prostate, and lung cancers [1]. These declines have been attributed to cancer prevention and early detection measures and effective cancer treatments [2]. Examples of effective cancer screening tests are Pap smears for cervical cancer, mammography for breast cancer, colorectal cancer screening, and perhaps prostate-specific antigen testing for prostate cancer. Smoking prevention also has reduced the incidence of lung cancer dramatically.

Unfortunately, however, not everyone in the United States has shared sufficiently in these interventions and has not benefited as well with respect to declining mortality rates [3]. These findings suggest that there is a disconnect between the nation’s discovery and delivery enterprises, between what we know and what we do. This discovery/delivery disconnect leads, at least in part, to the unequal burden of cancer, with resultant cancer health disparities (Fig. 1). Disparities occur when beneficial medical interventions are not shared by everyone in this country [4,5]. This unequal burden of cancer is a challenge to science and, more importantly, a moral and ethical dilemma for the United States [6].
The major declines in cancer rates can be attributed mainly to cancer prevention [6] and screening [7–11]. Declines in cancer mortality rates may be achieved through primary prevention or by screening and early detection coupled with timely and effective treatments. Effective cancer prevention and control activities cover the spectrum of cancer care from cancer prevention to early detection to effective diagnosis and treatment.

Causes of cancer health disparities

Disease always occurs within the context of human circumstances, and cancer is no exception. Three major determinants of health disparities among groups are culture, poverty (ie, low socioeconomic status), and the historical and current effects of social injustice (Fig. 2) [5]. It is important to distinguish between the meanings of these critical social variables.

The meaning of culture encompasses an individual’s or community’s shared communication system, similarities in physical and social environments, common beliefs, values, traditions, and world view, and similarities in lifestyle, attitude, perceptions, and behavior. Conversely, poverty is associated with a lack of resources, inadequate information and knowledge; substandard living conditions, risk-promoting lifestyle, attitudes, and behaviors, diminished access to health care, and poor nutrition (Fig. 3). Culture may augment or diminish poverty’s expected negative effects. Historically, social injustice has developed in the context of declaring certain population groups “inferior” to others. Currently, forms of social injustice, such as racism and racial discrimination, are factors in diminishing equal access to health care for some populations. The effects of these causal factors, namely culture, poverty, and social injustice, overlap with the relative importance of each factor changing with time. All aspects of the cancer continuum from cancer prevention, screening, early detection, diagnosis, treatment, and rehabilitation are impacted by these factors (see Fig. 2). Specific barriers to screening, diagnosis, and treatment can be...
viewed through the effects of these powerful socioeconomic determinants (Box 1). In the following discussion we examine these factors as they relate to barriers to screening, diagnosis, and treatment.

**Barriers related to culture**

It is important to distinguish between race and culture. Culture is not synonymous with race. Many cultures exist within any so-called racial group [6]. For example, there are many cultures in the Asian racial group, including Chinese, Japanese, Filipino, Korean, Vietnamese, and Thai. Each
### Box 1. Barriers classified by cultural factors, social injustice, and poverty factors

**Cultural barriers**

**Individual and role of culture**

Patient barriers related to educational information and their culture
- Lack of accurate cancer information
- Available information is unusable because of literacy, language, or cultural aspects

Barriers related to impact of culture and use of cancer care
- Cultural perspectives or biases, which may cause people to avoid screening
- Cultural belief about cancer and cancer fatalism, which may prevent people from seeking treatment
- Cultural perception of illness, which may affect diagnosis and treatment of cancer
- Cultural factors that play a role in acting on medical and caregiver preferences, including folk healing methods
- Cultural factors that determine how patients explain and tolerate pain
- Cultural perception of quality care
- Cultural behaviors that are risk prompting
- Lack of community support for screening activities

**Health care provider and culture**

Communication barriers
- Health care provider–patient relationship, understanding, and sensitivity to culture of patient

**Social injustice barriers**

**System barriers**

Limited access because of racial and ethnic issues
- Lack of physician recommendation for screening test/diagnosis/treatment based on racial discrimination
- Physician perception/biases toward racial groups
- Biases associated with treatment of racial and ethnic groups
- Racial profiling: doing harm by projecting stereotypes of a racial or ethnic group on an individual

**Poverty**

**Individual and poverty**

Financial barriers
- Financial issues that affect patient access to care
- Insurance status
has its own language, oral and written. Many Asian languages have multiple dialects, such as Mandarin and Cantonese for Chinese. Their cultures are as varied as the distinctive nature of their cooking. In the United States, however, they are all classified into one racial group, which is Asian.

Culture may influence the ability of an individual to understand the need to seek or accept cancer care and perceptions related to the likelihood of developing cancer. Culture may affect the capability to understand information on screening and cancer. Many sources of information on cancer are available; however, if an individual cannot understand the materials, such information is meaningless to that individual. Culture may promote risk-promoting lifestyles, such as heavy smoking, drinking of alcohol, or eating of fatty foods. Culture is a determinant of the beliefs and perceptions about cancer. In some cultures there is a tendency to be fatalistic

<table>
<thead>
<tr>
<th>Physical barriers</th>
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<tbody>
<tr>
<td>• Transportation</td>
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<tr>
<td>• Distance to cancer care</td>
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<tr>
<td>• Time off work or daycare issues</td>
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<tr>
<td>Barriers related to impact of culture and access to cancer care</td>
</tr>
<tr>
<td>• Poor provider–patient relationship</td>
</tr>
<tr>
<td>• Understanding provider information</td>
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<td>• Understanding patient needs</td>
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**Health care provider and poverty**

Financial barriers

- Financial issues that affect health care providers
- Insurance coverage
- Reimbursement costs and paperwork
- Failure to recommend screening
- Inadequate patient education

Communication barriers

- Do not share clinical information with patient
- Poor provider interaction with community

**Health care system and poverty**

Barriers that limit or prevent access to cancer care

- Underemphasis of cancer prevention
- Lack of screening facilities
- Limited education efforts
- Lack of treatment for uninsured
- Health insurance status
- Problem of paying for services
- Fragmentation of care
- Limitations on screening and treatment services
(eg, the perception that getting cancer is a death sentence). People with such an attitude do not seek or accept cancer screening or care. Cultural traditions may be a determinant of what treatments are acceptable, such as the use of folk medications rather than standard care. High death rates associated with treatment of late-stage disease may create the suspicion in a community that cancer treatment is a cause of death [12]. Recommendations by health care providers under such circumstances may be ignored. To overcome such barriers, there is a need to provide culturally and linguistically appropriate information and knowledge. Providers must understand the culture of their patients and the factors that can enhance their patients’ willingness to comply with their recommendations [5]. It should be noted that care providers also are of particular cultures, a factor that could influence health care–related decisions. We point out that all caregivers are acculturated and socialized before they are educated.

**Barriers related to poverty**

Recent data on cancer mortality rates by socioeconomic status document the disparities associated with poverty [13]. The 1995–1999 cancer mortality rates are reported by three levels of poverty: counties with <10% of people living below the poverty level, counties with 10% to <20% of people living below the poverty level, and counties with ≥20% of people living below the poverty level. For all cancer sites combined for all races, the ≥20% poverty group had the highest cancer mortality rates, with 13% higher rates for men and 3% higher rates for women than the <10% poverty groups [14].

The 1995–1999 cervical cancer mortality rates for the major racial and ethnic groups (non-Hispanic whites, blacks, Hispanics, Asians and Pacific Islanders, and American Indians/Alaska natives) have been shown to correlate directly to economic status. Within each population group, higher poverty rates were associated with higher mortality at the county level. For each racial or ethnic group, the 10% to <20% poverty group had a higher rate than the <10% poverty group, and the ≥20% group had the highest poverty rate. These rates demonstrate that poverty correlates with disparities within and between racial and ethnic groups [13].

A report on excess cervical cancer mortality showed that areas with high cancer rates also had high cardiovascular mortality rates and high infant mortality rates. High rates of cervical cancer mortality are sentinel markers that indicate larger, systemic health care issues that must be addressed by cancer control and other health care strategies [15].

The impact of poverty (low socioeconomic status) has major effects on disease incidence and access to screening and treatment. Forty-five million Americans do not have health insurance, and an estimated additional 35 million are underinsured [16]. Many of these people fall into a void, because they are too rich for Medicaid but too poor for Blue Cross insurance. Poverty is associated with risk and unhealthy diet and exposure to toxic environ-
ments. Poor people also have less information and knowledge, are less likely to undergo cancer screening tests, and are less likely to be informed of abnormal results on a timely basis [4–6]. Because of these factors and others, poor people tend to undergo initial treatment of cancer at later stages of disease.

Poverty also affects health care providers. Recent studies have suggested that low socioeconomic areas tend to have less well educated health care providers, such as fewer board-certified physicians [17]. As a result, some health care providers may not recommend screening tests or appropriate treatment to their patients. Physicians who practice in poor communities are less likely to be reimbursed appropriately for services rendered, which may affect the quality of service offered to patients. Sufficient resources may not be available to educate patients about screening. Few resources may make screening facilities and staff less available, affect the timely reporting of screening results, and diminish the quality of cancer treatment of uninsured and underinsured patients.

Poverty and culture are interrelated closely. We suggest that poverty acts through the prism of culture. Culture may augment or diminish poverty’s expected negative effects. Poverty is associated with inadequate physical and social environment, inadequate information and knowledge, risk-promoting lifestyles, attitudes and behaviors, and diminished access to health care, which result in decreased survival. Consider the people of Harlem, New York. They are mainly poor African Americans, many of whom smoke heavily, drink heavily, and eat a diet that is high in fat and salt. Similar lifestyles and behaviors are dominant in Harlan, Kentucky, where the people are poor and white [6]. In contrast, consider the members of the Seventh Day Adventists, a culture driven strongly by religious beliefs. Persons who follow the religion consume a vegetarian diet and neither smoke cigarettes nor drink alcohol. Even if a person is poor but is living in that culture, it is unlikely that the individual will develop lung cancer, because 90% of lung cancer is related to smoking cigarettes. Similarly, known health effects of excess alcohol use likely would be avoided. A diet high in vegetables and fruits seems to prevent disease. Clearly, health risks are driven by poverty and culture and not by race. In Figs. 4 and 5, cancer survival rates for all cancers combined by each racial and ethnic group are lowest for the higher poverty group [13].

**Barriers related to social injustice: the meaning of race**

In addition to culture and poverty, forms of social injustice, such as racism, discrimination and other kinds of bias, are critical factors in creating and maintaining disparities. Social injustice may be a factor in determining access to screening and cancer care.

Racial and ethnic categories in the United States are designated by the Office of the Management of the Budget (OMB). The OMB responsibility
stemmed from the government’s mandate to enforce civil rights laws (directive number 15 on race and ethnic standards for federal statistics and administrative reporting) [17]. Data were needed to monitor equal access to 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 decennial census but also in household surveys, on administrative forms, and in medical and other research. Currently, these racial and ethnic groups include whites, blacks, Hispanics or Latinos, American Indians and Alaska natives, Asians, native Hawaiians, and other Pacific Islanders [17].

The Institute of Medicine report “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” has shown evidence of racial bias in the distribution of cancer care [19]. These actions may include conscious decisions not to recommend screening or denying access to cancer treatments because of being in particular racial and ethnic groups. The Institute of Medicine determined that African Americans are less likely to receive standard treatments for cancer even at the same insurance and economic status. Bach and colleagues [17,20] showed that African-American patients were substantially less likely than white patients to undergo curative surgery for early-stage lung cancer, although they have the same insurance coverage and seem to be at the same economic level. In non-cancer
examples, Ayanian and colleagues [21] found that race is a major factor in who is referred for renal transplantation. An individual is more likely to be referred for transplantation if he or she is white rather than African American. Studies of emergency room experiences indicated that people also are treated for pain differently according to race. Compared with whites, African Americans and Hispanics are less likely to be treated with pain-reducing drugs when they have a long bone fracture, clearly a painful condition [22,23]. Evidence suggests that race does play a role in the provision of medical care. Patient bias also may play a role. Patients are less likely to follow screening diagnosis and treatment recommendations if they do not trust their doctors. False assumptions on the part of either the caregiver or the patient can have profound effects and may result in health care disparities [6]. Racial profiling may lead to errors in diagnosis and treatment. Racial profiling is stereotyping racial and ethnic groups and projecting those stereotypic characteristics on individuals in that group, which may lead to false assumptions that result in serious harm—intentional or unintentional—to individuals. For example, a health care provider may decide that a particular form of care should not be offered to an individual of a certain racial or ethnic group because of assumptions about the characteristics of members of the group, such as level of understanding and likelihood of compliance. Such actions may be unintentional but may have the effect that
an individual in a particular racial or ethnic group may be denied a beneficial intervention because of perceived racial and ethnic characteristics.

Another important related issue centers around the meaning and use of racial categories in science and society. On one hand, there is general agreement that racial and ethnic designation allows for monitoring for and correcting inequalities [18]. On the other hand, we conclude from population genetic and genomic studies that there is no biologic basis for the OMB classifications. OMB has stated that “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” [18,24]. Genomic studies have shown that clusters of ancestral origins correspond to country of origin rather than the OMB classifications. The OMB racial and ethnic classifications are used to monitor equity in our society. Consider the following points. Genomic studies have shown that Africans have the greatest genetic variation of any racial group. In the OMB classification, however, all African Americans are classified as one group. Hispanics are tied together by a common language and not by geographic or genetic bounds. In the OMB classifications, however, all Hispanics are grouped together. The dilemma occurs when the broad, nonscientific OMB classifications are used for scientific purposes, such as to determine if drugs are appropriate for specific racial and ethnic groups. The inappropriate use of racial and ethnic classifications could lead to misjudgments in treatment decisions.

In science and society, race is often used as a proxy for poverty, class, education, discriminatory experiences, and certain behaviors, among other factors. Such proxies frequently are misleading. Given the fact that human populations do differ and race is not the basis for those variations, however, scientists face the challenge of elucidating how populations really differ. To diminish disparities, we must look much deeper than race and ethnicity to find the real variables that cause disparities. Disparities may be caused by a lack of resources, cultural differences, lack of health insurance, or some complex array of these factors, for which race is only a surrogate measure. These factors somehow must be identified and quantified rather than attributing the differences to racial and ethnic groups. We must move away from assuming that being in a group is in itself the cause of disparity, except in cases in which the disparities are the result of inequity or social injustice [6].

**Patient navigation: the Harlem experience**

In recent years there has been progress in increasing screening rates in minority populations, particularly for breast cancer screening (Table 1) [25]. In the 2000 National Health Interview Survey, 68% of African-American women reported having had a mammogram in the last 2 years, compared with 71% of white women. The closing of the screening gap has not been reflected in a closing of the racial gap in mortality rates, however. The gap
between white and black female breast cancer mortality rates is still widening [3]. There seems to be a need for more than just screening rates to be comparable to reduce disparities. Early detection through screening does not reduce mortality unless such screening is followed by timely treatment.

We have determined that one way to promote timely treatment after a suspicious finding is through patient navigation. Patient navigators assure that any barrier a patient encounters in seeking diagnosis and treatment is eliminated (Fig. 6) [13]. This program operates on the paradigm that one can remove the effects of poverty, although poverty itself has not been reduced. The patient navigation concept and program were pioneered in Harlem, New York. The program was created to help address the barriers that poor people face in trying to obtain clinical follow-up services from an abnormal finding or cancer diagnosis and treatment. The patient navigator identifies, anticipates, and helps to alleviate the barriers that patients encounter. Patient navigators help patients to overcome the barriers before they become an obstacle to obtaining prompt and appropriate care [26,27].

In the 22-year period that ended in 1986, 606 patients (94% black) with breast cancer were treated at the Harlem Hospital Center. Almost all patients

### Table 1

Percent utilization of screening tests by race/ethnicity, education, health insurance and immigration status

<table>
<thead>
<tr>
<th></th>
<th>Mammograms in women ≥ 40 (within last 2 years)</th>
<th>Colorectal cancer screening in adults ≥ 50</th>
<th>Pap test in Women ≥ 25 (within last 3 years)</th>
<th>Prostate specific antigen test within year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Racial/ethnic Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>71</td>
<td>42</td>
<td>39</td>
<td>83</td>
</tr>
<tr>
<td>Black</td>
<td>68</td>
<td>40</td>
<td>32</td>
<td>84</td>
</tr>
<tr>
<td>AI/AN</td>
<td>52</td>
<td>37</td>
<td>28</td>
<td>75</td>
</tr>
<tr>
<td>Asian</td>
<td>59</td>
<td>34</td>
<td>27</td>
<td>71</td>
</tr>
<tr>
<td>Hispanic</td>
<td>61</td>
<td>27</td>
<td>27</td>
<td>77</td>
</tr>
<tr>
<td>Non-Hisp White</td>
<td>72</td>
<td>43</td>
<td>39</td>
<td>83</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High school</td>
<td>57</td>
<td>29</td>
<td>29</td>
<td>74</td>
</tr>
<tr>
<td>Some college</td>
<td>73</td>
<td>42</td>
<td>42</td>
<td>84</td>
</tr>
<tr>
<td>College graduate</td>
<td>80</td>
<td>52</td>
<td>48</td>
<td>88</td>
</tr>
<tr>
<td>Health Insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>38</td>
<td>19</td>
<td>18</td>
<td>62</td>
</tr>
<tr>
<td>Public</td>
<td>62</td>
<td>35</td>
<td>32</td>
<td>79</td>
</tr>
<tr>
<td>Private/Military</td>
<td>75</td>
<td>44</td>
<td>41</td>
<td>86</td>
</tr>
<tr>
<td>Immigration</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In US &lt; 10 years</td>
<td>39</td>
<td>20</td>
<td>16</td>
<td>61</td>
</tr>
<tr>
<td>In US ≥ 10 years</td>
<td>65</td>
<td>33</td>
<td>31</td>
<td>79</td>
</tr>
<tr>
<td>Born in US</td>
<td>71</td>
<td>42</td>
<td>39</td>
<td>83</td>
</tr>
</tbody>
</table>

**Abbreviations:** AI, American Indian; AN, Alaska Native.

were of low socioeconomic status, and almost 50% had no medical coverage. Approximately half were incurable at diagnosis (stages 3 and 4), and only 6% had early breast cancer (stage 1). From 1995 to 2000, 324 patients with breast cancer were diagnosed and treated at the Harlem Hospital Cancer Control Center. Of these patients, 70% were black and 26% were Hispanic. Approximately half of these patients had no medical insurance on initial evaluation. The study showed dramatic improvements in staging and 5-year survival rates. The results indicated that 41% of patients had stages 0 and 1 and only 21% of patients had stages 3 and 4. The 5-year survival rate was 70%, compared with 39% in the early Harlem Hospital Study [27].

Three factors accounted for the dramatically improved results demonstrated in the recent Harlem experience. First, the program offered free or low-cost screening mammography, which allowed for early diagnosis. Second, the patient navigator program promoted rapid resolution of abnormal findings and the initiation of treatment without delay. Third, the improved outreach and public education that was culturally appropriate were believed to have played important roles in removing the barriers to screening [26]. In June 2005, the President of the United States signed into law the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, modeled after the Harlem Project [28].

Summary

Disparities in cancer are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role. There is a critical disconnect between what we discover and what we deliver to
all Americans in the form of prevention, diagnosis, and treatment of cancer. This disconnect between what we know, at any given time, and what we do for the American people is in and of itself a major determinant of cancer disparities. Residents of poorer communities, regardless of race, have higher death rates from cancer. Viewed separately, within each racial and ethnic group, people who live in poorer counties have lower cancer survival. Evidence exists that race, in and of itself, is a determinant of the level of health care received. The biologic concept of race is untenable, but racial injustice—historical and current—is one of the determinants of cancer disparities. In this nation, we see, value, and behave toward one another through a powerful lens of “race.” This lens can create false assumptions that may result in serious harm to members of some racial and ethnic groups.

The following recommendations are provided to ensure that all patients receive the appropriate care [5].

Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services for breast, cervical, and colorectal cancer. Expand to include these services for other cancers when there is evidence that they are effective at improving survival.

Provide immediate medical coverage for uninsured and underinsured patients at the point of obtaining a suspicious result or diagnosis of cancer to ensure that no person with cancer goes untreated.

Delineate and target geographic areas with excess mortality with an intense approach to providing culturally relevant education, appropriate access to screening, diagnosis, treatment, and improved social support network.

Provide such communities with funding for patient navigator programs, the purpose of which is to provide personal assistance in obtaining timely and adequate diagnosis and treatment.

Establish and implement systems for monitoring treatment equity according to standards of care to diminish bias in the provision of health care.

Ensure that each individual, regardless of economic status, share in the responsibility for promoting his or her own health and well-being.

Final thoughts

There is a critical disconnect between what we discover and what we deliver to all Americans in the form of prevention, screening, detection, diagnosis, and treatment of cancer. This disconnect between what we know at any given time and what we do for the American people is, in and of itself, a major determinant of cancer disparities. We must identify and eliminate all barriers that prevent the benefits of research from reaching all people. Such barriers may be experienced at any point along the continuum of prevention, screening, diagnosis and treatment, and palliative care.
The United States has made progress in providing some forms of screening, such as for breast, cervical, and prostate cancer. We face a particular challenge in promoting and applying screening for colorectal cancer, which has the capability of markedly reducing death from colorectal cancer. Saving lives from cancer extends well beyond getting a particular screening test, however. Patients with suspicious findings at screening must be assured timely diagnosis and treatment. In communities of low socioeconomic status, patient navigation has proved to be an effective intervention in promoting such timely diagnosis and treatment when applied at the point of positive finding.

Geographic areas with excess cancer mortality should be delineated and targeted with an intense approach to providing culturally relevant education, appropriate access to screening diagnosis and treatment, and improved support systems, such as navigation.

The war against cancer has not been fought equitably on all fronts. We must tear down the economic, cultural, and societal barriers to early diagnosis and treatment of cancer. We must apply what we know, at any given time, to all people.

References


