



Intercultural Cancer Council 2006 Survivorship Report

Cancer Survivorship and the Medically Underserved: Reducing the Disparities in Cancer Care

Due to significant progress in the early detection and treatment of cancers, the United States is witnessing two trends that were virtually inconceivable even a decade ago. According to the American Cancer Society, for the first time in the nation's history, 2006 will see the first decline in cancer deaths in over 70 years.¹ Additionally, the National Cancer Institute reports the eye-opening statistic that the estimated 10.1 million cancer survivors in this country represent a tripling of the number of survivors from 1971 to 2002.²

Despite these gains, for Americans who are poor, lack health insurance, or otherwise have inadequate access to timely, high-quality cancer care -- including Americans of color and those who lack English language proficiency -- these trends remain illusionary. As reported by the landmark report, *From Cancer Patient to Cancer Survivor: Lost In Translation*, by the Institute of Medicine's (IOM) Committee on Cancer Survivorship: Improving Care and Quality of Life and by the National Cancer Policy Board (NCPB), minority, poor, and other medically underserved communities are least likely to be represented among cancer survivors.³ Because of disparities in healthcare delivery throughout the cancer care continuum -- from prevention, screening and diagnosis through cancer treatment, follow-up and end-of-life care -- these individuals are more likely to be diagnosed with late stage disease, experience poorer treatment outcomes, have shorter survival time³ with a lesser quality of life, and experience a substantially greater likelihood of cancer death.⁴

Compounding the problem, social inequities and racial discrimination are major factors precluding ethnic minority and poor populations from sharing equally in the gains in survivorship, resulting in disproportionately greater suffering and death from cancer. Besides patient cultural factors (e.g., language, values, traditions and level of trust in health providers), multiple studies confirm the adverse impact of health care providers' personal attitudes and perceptions towards patients due to race, limited English proficiency, and socioeconomic status.^{4,5} Although conducted at the subconscious level, such attitudes can lead to lingering racial and ethnic disparities across the health care continuum.

How significant is the gap in survival among minorities and other medically underserved communities, and what are the implications for the future? To answer these questions, the Intercultural Cancer Council (ICC) -- the nation's largest cancer organization whose mission is to promote policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories -- applied five criteria to quantify disparities in cancer

survivorship among the nation's minority and poor populations. Essential to a national comprehensive cancer control effort, these criteria address whether cancer care and services are Available, Accessible, Acceptable, Affordable, and Accountable to underserved populations.

The Gap in Cancer Survivorship

According to the IOM's *Lost In Transition* report, the composition of the survivorship population is determined by the dynamics of incidence (those diagnosed with cancer) and survival prevalence data (those presently living following a cancer diagnosis). Well represented in this group are those diagnosed with early stage cancers -- such as early stage breast or prostate cancer -- and a good prognosis. Conversely, poorly represented in the cancer survivorship population are those diagnosed with late-stage disease and/or who did not have access to quality clinical care.³

Applying this definition, new data from the American Cancer Society documents why medically underserved populations are the least likely to be represented among cancer survivors. As reported in *Cancer Facts & Figures 2006*, the cancer death rate for African American men is 40% higher than their non-Hispanic White counterparts, while African American women experience a cancer death rate 18% higher than non-Hispanic White women.⁶

In addition, specific types of cancer affect ethnic minority communities at rates several times higher than the national average. For example, the incidence of liver cancer (1998-2002) was nearly twice as high in Asian American and Pacific Islander (AA/PI) men as in African American men, and nearly three times the rate for non-Hispanic White men. Nationally, the incidence rate of cervical cancer is highest in Hispanic/Latina women (15.8%) versus rates for African American women (11.1%) and AA/PI women (8.9%), representing the second and third highest national cervical cancer rates, respectively.⁶ In California, however, where detailed cancer surveillance data are collected and reported for disaggregated AA/PI populations, Vietnamese women had the highest cervical cancer incidence (9.9%) and mortality rates (5.8%) (1988-2001), followed by Latinas, whose cervical cancer incidence and mortality rates were 5.3% and 4.5%, respectively, during the same period.⁷

Adding to these grim statistics, two other IOM reports charted racial and ethnic disparities in cancer rates and cancer treatment. The 1999 IOM report, *Unequal Burden of Cancer*, describes higher rates of specific cancers among racial and ethnic minorities, including higher rates of stomach cancer among Japanese, Korean and Vietnamese American populations, higher liver cancer rates among Southeast Asian, Korean and Chinese populations, and the highest rates of colon and rectal cancers among Alaska Natives populations.⁸ The 2003 IOM report, *Unequal Treatment*, reported significant racial and ethnic disparities in receipt of appropriate diagnostic tests and treatment for cancer leading to poorer survival and higher death rates for minority and poor patients.⁹

While differences in race and ethnic background are clearly significant, *Lost In Transition* reports poverty to be a significant factor in poorer survival rates among medically underserved populations. Across all racial and ethnic groups, the overall five-year survival rate is greater than 10% higher for persons who reside in affluent areas.³ Compared to only 8% of non-Hispanic Whites living in poverty, 24% of African Americans and 22% of Hispanic/Latinos live below the

poverty line, which significantly influences the prevalence of underlying cancer risk factors, such as tobacco use and obesity, as well as access (or lack thereof) to screening services and cancer care.⁶

Confirming the impact of poverty on cancer mortality, and in stark contrast to encouraging national trends,^{1,2} a 2003 National Cancer Institute (NCI) monograph¹⁰ reveals:

- Over a 20-year period, mortality from cancers increased 13% among low-income men, and by 3% among low-income women.
- For each of the cancers studied, for both men and women, the highest percentage of late-stage cancer diagnoses occurred among the poorest populations.
- For all cancers combined, men and women residing in high poverty neighborhoods experienced the lowest cancer survival rates.
- Among men diagnosed with cancer between 1988 and 1994, the overall five-year survival rate (for all cancers combined) was 61%, but only 49% for men residing in high poverty areas.
- Among women diagnosed with cancer between 1988 and 1994, the overall five-year survival rate was 63%, but only 53% for women who lived in high poverty areas.¹⁰

The end result of being poor is that medically underserved communities are grossly underrepresented in the cancer survivorship population. This is especially true for African Americans who make up approximately 13% of the U.S. population (2000), but comprise only 8% of U.S. cancer survivors. However, a growing body of evidence finds that lower survival rates exist among all U.S. racial and ethnic groups and the common denominator is lack of access to quality care, which is inevitably linked to poverty.¹⁰

Differences in Availability/Accessibility of Cancer Prevention and Early Detection

Evidence suggests that many types of cancer can be prevented and the prospects for surviving cancer will continue to improve if patients have access to state-of-the-art preventive and diagnostic services and early treatment. However, numerous studies document major disparities in primary cancer prevention, such as smoking cessation and improved dietary habits, as well as less access to and use of effective cancer screening services among the nation's minority and poor populations.

Although not intended as a conclusive analysis, the following is a review of how minorities and the medically underserved are faring when it comes to cancer prevention programs, screening services, and early detection methods.

1. Tobacco Use

In the United States, tobacco use accounts for at least 30% of all cancer deaths and 87% of lung cancer deaths.⁶ Moreover, smoking is associated with increased risk for at least 15 types of cancer – nasopharynx, nasal cavity and paranasal sinuses, lip, oral cavity, pharynx, larynx, lung, esophagus, pancreas, uterine, cervix, kidney, bladder, stomach, and acute myeloid leukemia.⁶

While overall smoking rates have dropped dramatically over the past two decades, an estimated 45 million adults currently smoke, and among smokers, many are racial and ethnic minorities.¹¹ American Indians and Alaska Natives are more likely to smoke (33.4%) than all other U.S. population groups,¹² although marked variation in smoking prevalence exist between Tribal groups.¹³ Self-reported data from the 2004 National Health Interview Survey indicate that non-Hispanic Whites have the second highest smoking prevalence rates (22.2%), followed by African Americans (20.2%).¹² Hispanic/Latino (15%) and AA/PI populations (11.3%) are reported to have lower smoking prevalence than other groups.

However, disaggregated local and regional studies reveal significant differences in intra-group smoking rates.^{12, 13} For example, while the 2000 aggregate smoking rate for AA/PI adults was 13%, disaggregating these two population groups uncovers distinct rates of 17% versus 13% for Pacific Islanders and Asian Americans, respectively¹³ (note that Pacific Islanders comprised approximately 6.7% of AA/PIs in 2004).^a

Further disaggregation of Asian American groups also reveals appreciably higher smoking prevalence among men than women for all Asian American groups.¹¹⁻¹⁴ Additionally, due to the high percentage of U.S. immigrant Asian populations (69% in 2000) and because most health surveys are conducted in English (and sometimes in Spanish), results from multilingual health surveys have revealed considerably higher AA/PI smoking rates than previously reported.¹⁴

A major review by the Intercultural Cancer Council (ICC) Caucus confirmed that tobacco continues to be a serious problem among the socioeconomically disadvantaged.¹⁵ More individuals from households with an annual income of less than \$25,000 smoke cigarettes compared households with incomes of \$25,000 or more (35.5% vs. 26.5%, respectively). Additionally, individuals who have not graduated from high school are more likely to smoke cigarettes than those who completed high school education or higher (35.4% vs. 26.8%, respectively).¹⁵

Smoking is also a major problem among specific minority groups, those living on or near Indian Reservations, the rural poor, and other medically underserved populations. According to recent statistics:

- In 2004, 24% of African American men reported that they were current smokers.¹² Smoking is responsible for 87% of lung cancers. African American men are nearly 50% more likely to develop lung cancer and 35% more likely to die from lung cancer than non-Hispanic White men.⁶
- Smoking among African American youth is on the rise. According to the Centers for Disease Control and Prevention (CDC), cigarette smoking increased in 1999 among African American high school students, leading to smoking rates of approximately 34% among young African American men and 23% among young African American women smoke.¹⁶

^a Calculated from July 1, 2004 Population Estimates, Table 3: Annual Estimates of the Population by Sex, Race and Hispanic or Latino Origin for the United States: April 1, 2000 to July 1, 2004. U.S. Census Bureau, <http://www.census.gov/popest/national/asrh/NC-EST2004/NC-EST2004-03.xls>.

- The prevalence of cigarette smoking is higher for all American Indian tribes (41.7% for men and 38.1% for women), except Arizona women, in comparison to general population rates (men 23.6% and women 16.7%).¹⁷
- The CDC's 1999 Youth Risk Behavior Surveillance System (YRBSS) found that about one-third of Hispanic high school students in grades 9 through 12 were current cigarette smokers.¹⁶ Smoking prevalence increased by one-third among Hispanic students from 1991 (25.3%) to 1997 (34.0%).¹⁸

Disparities in smoking prevalence also exist between states and U.S. associated territories.¹⁹ Some examples include:

- Kentucky (27.6%), West Virginia (26.9%), Oklahoma (26.1%), and Tennessee (26.1%) had the highest smoking prevalence rates among all U.S. states in 2004.¹⁹ Not surprisingly, these states are either Southern (WV, TN), largely rural (KY, WV, OK, TN), fall within Appalachia (KY, WV, TN), have low household income rates (KY, WV, OK, TN) or high poverty rates (KY, WV, TN), all of which are determinants of high smoking prevalence.²⁰
- In 2003, Guam had the highest smoking prevalence rate among U.S. territories (34%), compared to low smoking rates in Puerto Rico (13.6%) and the U.S. Virgin Islands (10%).²¹ The markedly higher smoking rate in Guam is likely attributable, in part, to the tobacco industry's aggressive international marketing campaign to increase smoking in Asia and the Pacific.²²

Reducing racial and ethnic disparities in tobacco use will require comprehensive tobacco control programs, especially focused on preventing minorities and the poor from starting to smoke, helping them quit using all tobacco products, reducing exposure to secondhand smoke, and limiting the impact of tobacco advertising and marketing in minority and disadvantaged areas.¹⁵ While the ICC Caucus supports the CDC's funding guidelines recommendations for programs in all 50 states and the District of Columbia,¹⁵ the American Cancer Society reported in 2004 that only four states -- Colorado, Delaware, Maine and Mississippi -- had invested at least the recommended amount for tobacco control programs.¹¹ Thus, much still needs to be done to reduce tobacco use and exposure.

2. Cancer Screenings

The IOM's *Lost In Transition* report finds that a critical factor in cancer survivorship is the availability of screening tests for major cancers, which has greatly increased the number of long-term survivors living with preclinical and treatable early-stage disease.³ Accordingly, the report charted the differential use of cancer screenings among men and women, confirming that minorities and the underserved are the least likely to receive preventative and screening services, such as Pap smears, mammography, PSA tests and colonoscopies.

Because half of cancer survivors today have been diagnosed with cancers of the breast, prostate, colon and rectum, the IOM report also examined the use of effective screenings for these cancers and found the following:³

- For women with breast cancer, rates of mammography were significantly lower among American Indians and Alaska Natives (AI/AN) relative to their White counterparts (37% vs. 57%, respectively). This lower rate of screening likely accounts for the relatively low percentage of AI/ANs diagnosed with localized breast cancer as compare to non-Hispanic Whites (56% vs. 66%, respectively).
- African American women are more likely to be diagnosed with later stage tumors, which are associated with a poor outcome.
- AI/AN men are much more likely than non-Hispanic White males to have their prostate cancer detected at a more advanced stage (12% vs. 5%, respectively), while African American men are somewhat more likely than non-Hispanic White men to have advanced disease at diagnosis (7% vs. 5%, respectively).
- Screening rates for colorectal cancer are lower among the poor, recent immigrants, people with lower educational levels, and Hispanic/Latinos.
- Colorectal cancer incidence and mortality rates are highest in African American men and women. Moreover, African Americans and AI/ANs are more likely than non-Hispanic Whites to be diagnosed after their disease has spread beyond the bowel wall.³

Reinforcing these findings, research compiled by the Intercultural Cancer Council and the ICC Caucus shows:

- Minority women and women with low-income levels are significantly less likely to practice appropriate mammography and Pap test screening.¹⁵
- Between 60% and 80% of American women with newly diagnosed invasive cervical cancer have not had a Pap test in the past five years. In particular, Asian American, Hispanic/Latina, low-income and less educated women are less likely to report having regular Pap tests.¹⁵
- Compared to women in households with incomes of \$50,000 or more, those in households with incomes of less than \$25,000 receive less Pap tests (88.9% vs. 80.3 %, respectively).²³
- Fewer women in Appalachia receive Pap tests compared to women living outside of this region (72.5% vs. 80.8%, respectively).²³
- Only 48% of Filipino American women and 41% of Korean American women obtain recommended Pap screening tests.²⁴
- Only 38% of Hispanic women aged 40 and older have regular screening mammograms.¹⁵
- Hispanic/Latinos are less likely than non-Hispanic Whites to report having had a screening test for colorectal cancer.¹⁵
- Further, although Filipino Americans are second only to American Indians as the U.S. population group the poorest survival rates for colorectal cancers,¹⁵ only 25% of Filipino American women receive adequate and timely colorectal cancer screening.²⁴

In order to reduce these disparities in cancer screening utilization, we must address these unequal patterns of access to standard care through private and public initiatives, including the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which has facilitated access to breast and cervical cancer screening programs for low-income, uninsured and medically underserved women.¹⁵ Another promising initiative is the NCI-funded Patient

Navigation Research Program (PNRP; established in 2002), which is conducting several pilot tests to identify ways to give minorities and the poor access to cancer prevention, screenings and treatment along with an advocate who can help the underserved navigate through today's complicated health care system.²⁵

Availability/Accessibility/Acceptability of Cancer Therapies and Adjuvant Treatment for the Medically Underserved

In addition to cancer prevention and screenings, *Lost In Transition* reports that access to state-of-the-art cancer treatments and clinical trials is another predictor of cancer survivorship.³ Thus, ICC provides the below assessment of the extent to which minority and the medically underserved communities have timely access to the full range of quality cancer therapies and adjuvant treatments currently available.

1. Access to State-of-the-Art Cancer Treatments and Clinical Trials

Studies indicate that, following a cancer diagnosis, minorities and medically underserved patients are less likely to receive state-of-the-art cancer care, including access to cancer clinical trials and treatment with novel, new targeted cancer therapies,¹⁵ as evidenced by these examples of treatment disparities:

- Overall, only 2% to 3% of adult cancer patients participate in cancer clinical trials, with the elderly, racial and ethnic minorities and the medically underserved even less likely to participate.¹⁵
- American Indians and Alaska Natives who have less than a college degree are rarely included in any type of cancer clinical trials.¹⁷
- African Americans and Native Americans treated for colorectal cancer receive less intensive therapy and have poorer survival than White patients.¹⁵ In addition, older colorectal cancer patients are less likely to receive adjuvant chemotherapy after surgical removal of a colon or rectal tumor than younger patients, partially because of increased chemotherapy toxicity in the elderly.¹⁵
- A major study on quality of breast cancer care for women living in New Mexico found significant disparities in time to first cancer-directed surgery for American Indian women for every interval examined, compared to non-Hispanic White women. Controlling for age, stage, grade and census-tract poverty-level, American Indian women were four times more likely to receive their first cancer-directed surgery more than six months (186 days) after diagnosis.¹⁵

To increase the number of long-term, disease-free cancer survivors, the *Lost In Transition* report underscores the need to improve access by the medically underserved to cancer clinical trials and novel, new targeted cancer therapies.³ This includes overcoming fears about experimental treatments, which the Coalition of National Cancer Cooperative Groups has identified as one of the biggest barriers to enrollment in cancer clinical trials.³ Continued advocacy to ensure Medicare, Medicaid and other government reimbursement programs cover more targeted therapies is also needed; while this may be more expensive, it has been shown to be effective.³

2. Minorities, the Medically Underserved and Pain

For more than one million Americans diagnosed with cancer, pain is a very real and critical health issue. While greater than 70% of people with advanced cancers experience pain, less than half receive treatment for adequate pain management.²⁶

While pain is a distressing condition for all cancer patients, a number of studies have concluded that minority and medically underserved patients experience high prevalence rates for unrelieved pain and are significantly less likely than non-Hispanic White patients to receive prescriptions for analgesic agents, putting them at serious risk for inadequate pain control. The latest pain statistics compiled by ICC illustrate the extent to which minority and medically underserved cancer patients are at high risk for and suffer from a disproportionate burden of cancer pain:²⁶

- A major pain study of minority cancer patients and their providers found that 28% of Hispanic/Latinos and 31% of African Americans with metastatic or recurrent cancer receive analgesics of insufficient strength to manage their pain.²²
- Metastatic cancer patients who receive treatment at centers with a predominantly minority patient population are three times more likely than those treated elsewhere to experience inadequate pain management.
- A patient's ethnicity has a greater impact on the amount of opioid prescribed by the clinician than on the amount of opioid self-administered by the patient.
- African American and Hispanic patients with severe pain are less likely than their non-Hispanic White counterparts to be able to obtain commonly prescribed pain medications, because many pharmacies in minority communities do not carry adequate stocks of opioids.
- The percentage of patients with inadequate pain treatment is significantly higher in community clinical oncology programs that treat predominantly African American and Hispanic patients than in other clinical settings, demonstrating that the type of treatment facility also influences pain treatment among minorities.
- Few minority patients are told in advance about potential side effects from pain medicines or how to manage them.
- Research on culture and quality-of-life issues, including pain symptom management, has long been neglected. Most pain literature acknowledges that culture influences cancer pain management, yet little empirical work has been conducted to confirm this.
- Cultural beliefs and attitudes about coping with pain may explain why some Asian patients are less likely to request an opioid for severe pain, or cease its use prematurely even though they receive some pain relief.
- Physicians often do not understand patients' expressions of their pain symptoms. For minority and immigrant patients, language barriers, the patient's low health literacy, and/or lack of education often exacerbate the situation. Unfortunately, few physicians are trained or otherwise knowledgeable about cultures different from their own.

Based on research reviewed by ICC, the two critical factors contributing to increased risk of under management of cancer pain are 1) administration of treatment at medical institutions that serve primarily minority patients, and 2) patient/physician discrepancy in the estimation of pain

severity. Addressing these factors requires effective advocacy to improve the delivery of cancer care in community treatment centers and more community-based education, especially to help minority cancer patients better describe their pain.²²

Late-Term Effects of Cancer and the Medically Underserved

While minorities and the medically underserved are less likely to be represented among cancer survivors, the health of those who survive their cancer treatment will be forever altered. According to the IOM's *Lost In Transition* report, the consequences of cancer and its treatment -- referred to as "late-term effects" -- may occur immediately or several years after treatment ends, and can include cancer recurrence, a secondary cancer, and increased risk for cardiovascular disease, osteoporosis, or other chronic health conditions.³

Although limited data exists regarding the prevalence of late-term effects, the consensus is that such effects are now common. While secondary cancers are perhaps the most frequent life-threatening late effect, a number of tissues and body systems can be impaired as a result of certain chemotherapeutic agents, leading to post-treatment fatigue, urinary problems, neurological symptoms, and even congestive heart failure. For these reasons, the IOM report classifies cancer as a chronic disease, in part because of the serious consequences and persistent nature of some of cancer's late effects throughout the patient's life.³

At the same time, adverse effects are not limited to physical problems. Research shows that many survivors and their families experience significant psychosocial effects, including fear of recurrence, sense of isolation, anxiety, depression, employment and insurance discrimination, altered body image, and relationship difficulties. For example, cancer survivors from ethnic minority and lower educational backgrounds are less likely to return to work after conclusion of cancer treatment.²⁷ Accordingly, the National Cancer Institute report, *Plans & Priorities for Cancer Research*, states: "It is clear that for those who have finished treatment, being disease free does not necessarily mean being free of their disease."²⁷

In terms of monitoring for late effects, the IOM examined those cancers that account for more than half of the survivorship population: breast, prostate, colorectal, and Hodgkin's disease. Looking at the challenges facing breast cancer survivors, the IOM report found:³

- Women with a history of breast cancer are the largest group of cancer survivors, representing 22% of the survivorship population.
- Recurrence of breast cancer can occur more than 20 years after primary therapy
- Women with a history of breast cancer are at risk for developing another cancer, independent of the first occurrence.
- Lymphadema is a common late effect of surgery and radiation therapy and can occur up to four or more years following treatment.
- As many as one-third of breast cancer survivors report fatigue one to five years after diagnosis.
- Breast cancer survivors are at increased risk for sexual dysfunction, premature menopause, osteoporosis, musculoskeletal complaints, cardiovascular disease and adverse cognitive effects.

- Poor communication with physicians and lack of access to follow-up mammograms are major factors associated with poorer outcomes for breast cancer survivors.
- Although limited research exists on racial or ethnic differences in quality-of-life among women diagnosed with breast cancer, existing studies find that differences in outcomes among African American and non-Hispanic White breast cancer survivors are attributable to socioeconomic and life-burden factors.³
- Additionally, outcome disparities may also be attributed to differences in stage at diagnosis and biological determinants (grading) between African American and non-Hispanic White women.²⁸

For men with a history of prostate cancer, representing 17% of the survivorship population, the IOM report finds:³

- All of the treatments for localized prostate cancer have side effects that can profoundly affect the individual's sexual, urinary and bowel function.
- Rates of bladder cancer appear to be higher than expected among men with prostate cancer.
- Osteoporosis is a potentially serious complication of androgen deprivation therapy for prostate cancer and requires preventative measures such as supplementation with calcium and vitamin D.
- Androgen deprivation therapy for prostate cancer may also be associated with impaired memory, attention and other cognitive effects.

Regarding survivors of colorectal cancer, the IOM report³ documented the following findings:

- Up to 40% of cancer survivors treated for local or locally advanced colorectal cancer will experience recurrent disease.
- Survivors of colorectal cancer are also at risk for developing a second primary colorectal cancer.
- The risk of other cancers developing is higher among survivors of colorectal cancer, including cancers of the small intestine, cervix, uterus, and ovary.
- Depression is more prevalent among survivors of colorectal cancer, especially those with permanent colostomies.
- Survivors of colorectal cancer can experience poor sexual function and bowel dysfunction.
- Poor communication with physicians and lack of access to follow-up surveillance testing, especially colonoscopy, are major factors associated with poorer outcomes for colorectal cancer survivors.

Because these risks are significant, the IOM report stresses the need for post-treatment survivorship care but states that the current system for delivering care is inadequate, especially for medically underserved cancer survivors.³ Barriers identified by the IOM report are: 1) a fragmented and poorly coordinated cancer care system; 2) the absence of a focus of responsibility for follow-up care; 3) poor mechanisms of communication; 4) lack of guidance related to specific tests, examinations, and advice that make up survivorship care; 5) inadequate

reimbursement from insurers for some aspects of care; and 6) limited experience on the best way to deliver care.³

While these problems apply to all cancer survivors, certain barriers exacerbate the access to effective post-treatment care for medically underserved population, such as difficulties in communications between patients and physicians. This is especially true for the 90 million American adults who lack the necessary literacy skills to effectively utilize the U.S. health care system.³ Those most severely impacted are individuals with a limited education or with limited English proficiency.

The IOM report also identifies access barriers resulting from the personal attitudes and perceptions of health care providers related to a patient's race and socioeconomic status.³ Moreover, the report finds that the same problems the medically underserved face gaining access to cancer prevention and screening programs around the initial diagnosis remain for those who survive their cancer. Thus, an important priority will be to increase the number of community-based survivor programs directed to racial and ethnic minorities and the poor.³

Affordability and Accountability of Cancer Care and the Medically Underserved

Because the chances for surviving cancer increase dramatically when the disease is detected early and patients have access to quality cancer care, one of the most significant reasons for the disparity in cancer survival among minority and medically underserved communities is lack of health insurance.³ According to the *Lost In Transition* report, access to health insurance influences the amount and quality of the health care received, which in turn impacts survival.³

This finding increases in relevance as the most recent (March 2006) Census Bureau figures reveal that the number of Americans continues to grow; 46 million Americans (15.5%), including more than 8 million children, are presently uninsured.²⁹ Between 2003 and 2004, the percentage of Americans with employment-based medical insurance declined from 60.4 % to 59.8%, respectively.²⁰ 2004 Census Bureau data indicate that 32.7% of Hispanic/Latinos were uninsured, followed by 19.7% of African Americans, and 16.8% for Asian Americans. The two-year (2003-2004) average uninsured rate for American Indians and Native Americans was 29.1%, followed by Native Hawaiians and other Pacific Islanders at 21.3%.²⁰ In 2004, 26.7% of the uninsured population were immigrants; totaling 11.5 million uninsured individuals and comprising 33.7%, nearly two-and-a-half times that of the native born population (13.3%).²⁰

When it comes to the newly diagnosed cancer patient, the 2004 IOM report, *Insuring America's Health: Principles and Recommendations*, linked lack of insurance with less preventative and screening services (such as Pap smears and mammograms), and less treatments that meet professional standards of care (such as breast-conserving surgery versus mastectomy).³⁰ As a result, the report found uninsured adults face a 25% greater mortality risk than adult Americans with health care coverage.

Not surprisingly, these same challenges apply to uninsured cancer survivors; for example, the risk of dying for uninsured women with breast cancer is 30% to 50% higher than for women with breast cancer who are covered by medical insurance.³⁰ In the *Lost In Transition* report, the IOM

estimates that 11% of cancer survivors (approximately 572,000 individuals in 2005) had no medical insurance.³ Uninsured rates increase dramatically for younger survivors, 25 to 44 years of age (19%) and Hispanic/Latino survivors (26%).³

These uninsured adult cancer survivors are less likely than insured survivors to receive follow-up monitoring, and they have higher out-of-pocket spending burdens for medical care.³ In particular:

- Expenditures for treating the uninsured are significantly less than for survivors with health insurance. One study of non-elderly cancer patient without insurance revealed that medical expenditures were under half (57%) that of privately insured patients over a six-month period.
- Among uninsured cancer survivors, ages 24 to 64 years, many report access problems due to financial concerns, including delays in obtaining medical care (51%), inability to access needed care (44%), and inability to obtain needed prescription medications (31%).
- Compared to insured cancer patients, the three-year relative cancer survival rate is markedly poorer for those patients without health insurance.

Beyond the problems for the uninsured, the *Lost In Transition* report confirms previous concerns about limited access to public insurance coverage.³ 2004 Census Bureau data reveal that Medicaid and Medicare -- the nation's leading safety net programs for health care access -- covered 37.5 million (12.9%) and 41.6 million (13.7%) Americans, respectively.²⁰ Despite an increase in coverage of 2.3 million people from 2003 (78.8 million people; 26.6%), greater than 15 million poor Americans remain without health insurance,²⁰ since only children, parents of dependent children, and pregnant women qualify for coverage by Medicaid, and only the elderly and disabled qualify for Medicare coverage.²⁰ In many states, adults who fit one of these categories must also live on income far below the federal poverty level to qualify for government health coverage, forcing many uninsured individuals to "spend down" their assets in order to meet income criteria.³

Since 2000, all 50 states have agreed to provide Medicaid coverage to poor women who obtained a breast or cervical cancer diagnosis through CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP).³ Although Medicaid reports that coverage ends when the woman's course of treatment is completed, IOM's Survivorship report expresses confusion regarding which services are covered, as well as how individual states define "completion of treatment".³ Moreover, the report suggests that NBCCEDP is severely limited, since it reaches fewer than 15% of all eligible women based upon age, income and insurance status.³

To overcome such disparities, in their report, *Insuring America's Health*, the IOM Committee on the Consequences of Uninsurance envisions an approach to health insurance based on five basic principles:³⁰

1. Health care coverage should be universal.
2. Health care coverage should be continuous.
3. Health care coverage should be affordable to individuals and their families.
4. The health insurance strategy should be affordable and sustainable for society.
5. Health insurance should enhance health and well being by promoting access to high-quality care that is effective, efficient, safe, timely, patient centered, and equitable.

These principles are encompassed within *Healthy People 2010*,¹³ which includes the goal of providing health care coverage for all Americans by the end of the decade, including coverage for effective clinical screening services, such as cancer screenings. These principles also concur with ICC's objective that the essential component of a national comprehensive cancer control effort must ensure that cancer care and services are Available, Accessible, Acceptable, Affordable, and Accountable across the cancer care continuum for all cancer survivors.

Although health insurance by itself is not sufficient to eliminate disparities in cancer care, it will allow minority and medically underserved cancer survivors, their families and health care providers to focus on timely access to quality post-treatment follow-up care and monitoring, in order to achieve long-term cancer-free survival with optimum quality of life.

Looking Ahead

Demographic trends clearly show increasing diversification of the nation's population.²⁰ Equally evident is the impact of racial, ethnic and socioeconomic disparities on healthcare delivery at all points along the cancer care continuum -- from prevention, screening and diagnosis through state-of-the-art cancer therapies, follow-up and end-of-life care -- resulting in poorer cancer outcomes and lower survival rates.^{3, 4,6,9-14,20,23-25,27} As a result, minorities and the medically underserved are the least likely to be represented among cancer survivors. Even when underserved cancer patients achieve 5-year survival, the likelihood that late-term effects of their disease will go untreated is high. In addition, high poverty rates among minority and poor communities mean that many fall into the growing group of uninsured Americans, who are less likely than insured survivors to receive follow-up healthcare monitoring, and will experience higher out-of-pocket spending burdens.

Elevating the needs of minorities and the medically underserved must be a priority for policy makers, the healthcare industry, public health workers and educators, medical providers, survivorship communities, and the public at large, as we work together to address the future of quality cancer survivorship care. Eliminating the unequal burden of cancer will require equal access to timely and quality services and programs at every stage along the cancer care continuum for everyone, including minority, the poor and other underserved populations in the 50 United States, throughout Indian Country, and all U.S. associated territories.

Disparities in cancer care have reached crisis proportions, but this issue has not yet achieved the level of public attention or commitment of financial and human resources that it requires and deserves. The Intercultural Cancer Council believes all Americans deserve the same opportunity to achieve quality, long-term cancer survivorship and to have assurances that their future health care needs will be properly and proactively managed.

One out of every two men and one of every three women in the U.S. develops cancer during his or her lifetime;³ it's time we work together to tackle these problems. Join us, won't you?

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The Intercultural Cancer Council is an advocacy organization whose mission is to advance policies, programs, partnerships and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations.

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