

Equitable Access to Cancer Services

A Review of Barriers to Quality Care

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BACKGROUND. Barriers to cancer care have been documented in nearly all settings and populations; such barriers represent potentially avoidable morbidity or mortality. A conceptual framework was used to describe patient, provider, and system barriers to cancer services.

METHODS. A review of the English language literature on cancer care from 1980–1998 was conducted; key research was summarized for each domain in the conceptual model.

RESULTS. Key patient barriers are related to old age, minority race, and low socioeconomic class; the common pathways by which these sociodemographic factors appear to mediate cancer outcomes include social class and race-related or class-related attitudes. Providers are often ill-prepared to communicate the complexities of cancer care to their diverse patient populations; constraints of the medical care system also can impede the delivery of care. To the authors' knowledge the impact of the rapid growth in managed care organizations (MCOs) on access to care has yet to be evaluated fully. Although MCOs historically have provided high levels of cancer screening in healthy populations, to the authors' knowledge there are fewer data regarding outcomes for elderly and poor populations and for treatment services.

CONCLUSIONS. Additional research is needed to develop and test interventions to overcome barriers to care and evaluate the impact of the growth of managed care on access to cancer care for diverse populations. *Cancer* 1999;86:2378–90.

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Each year, millions of men and women in the United States undergo cancer screening; 1.2 million will develop cancer, and more than 550,000 will die from their disease.¹ Access to quality care can have a substantial impact on cancer outcomes. Unfortunately, problems with access to cancer services have been documented in nearly all settings and populations.

In this article, a conceptual framework was used to describe barriers to quality cancer services over the full spectrum of cancer care, from secondary prevention to end of life care, and to suggest interventions for the improvement of access to quality care and cancer outcomes.

Conceptual Framework

Access has been defined as “the timely use of affordable personal health services to achieve the best possible health outcomes.”² The process of gaining access to care represents dynamic interactions of diverse individuals in their social context interfacing with health care providers who, in turn, are operating in a variety of changing and

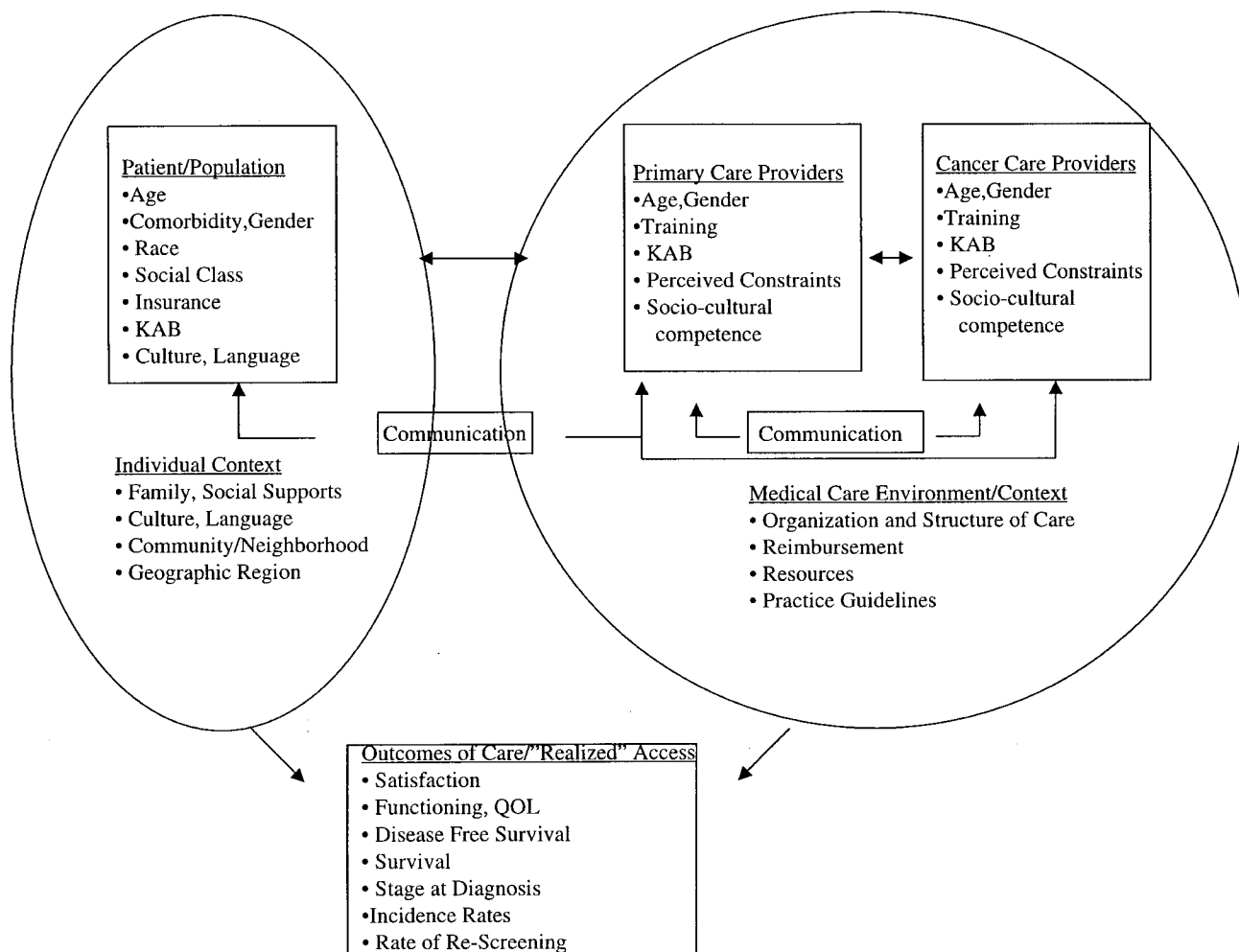


FIGURE 1. Model of access to cancer care. KAB: knowledge, attitudes, and (health) behaviors; QOL: quality of life.

often constrained medical care structures and environments. To depict this broad and interactive process, we have adapted the behavioral models of access to medical care from Andersen^{3,4} and Aday et al.⁵ to reflect access to cancer care (Fig. 1). Because primary care providers often are an important source of care for cancer patients and may be responsible for initiating orders for screening services and/or coordinating services, both primary and cancer care providers are included in the model. We have also added patient-provider and provider-provider communication as key model components.

An important component of our model was the inclusion of "realized access" to care. We have expanded the original definition of realized access from measures of utilization and satisfaction⁴ to include all outcomes of cancer care. Outcome measures are important for two reasons. First, having a quantifiable end point is necessary to determine whether access

has occurred and has had the intended effect. Second, defined outcomes are an integral part of quality measurement.⁶⁻⁸

This model can be applied to evaluating access to cancer care throughout the continuum of cancer care. First, individuals (and populations) must gain access to early detection services. Next, if a screening test is abnormal, then diagnostic services must be available. For those who are diagnosed with cancer, staging evaluation precedes and often determines treatment. Patients surviving their disease also need to have access to on-going surveillance, so that recurrences can be recognized promptly and treated. For those who will die of their disease, having access to end of life care is critical. Thus, access has different dimensions and outcomes across the spectrum of cancer care: Some domains may be more relevant for a particular phase of care but less important for others. Finally, this framework can be used as the basis for designing and

evaluating interventions addressing specific types of barriers.

BARRIERS TO CANCER CARE

The section below uses our framework to describe barriers to cancer care in each of the model domains: patients, physicians, patient-physician communication, and the health care system.

Patient Barriers

Figure 1 shows that there are many patient factors that can act as potential barriers to care, including demographics (patient age, gender, insurance, social class, race, and geography), language and acculturation, attitudes, and family and cultural contexts. Cancer is a disease of old age,⁹ yet there is limited research on barriers to cancer screening, treatment, and posttreatment care among the elderly. The potential effects of age on access to cancer care are multifaceted. First, the elderly often underestimate their risk of cancer.¹⁰ Second, along with increasing risk of cancer with age, the elderly have an average of three or more chronic medical conditions.^{11,12} The life expectancy of most elderly women (and men), however, appears to be sufficiently long to realize benefits from cancer screening,¹³ although research on the impact of comorbidity on cancer screening use and survival outcomes has been limited and inconsistent.^{12,14-22} Third, cognitive impairments, which are more frequent in elderly patients than in younger patients, also have been noted to affect cancer treatment, with the more impaired elderly patients receiving less definitive care for carcinoma of the breast and colon cancer compared with patients with lower levels of impairment.²³ Finally, the elderly are represented disproportionately in the lower social classes and have high rates of poverty, underinsurance, and out-of-pocket costs.^{24,25}

Gender effects on access are less clear. For instance, although men have lower rates of use of routine medical care in the absence of symptoms than women, affording less opportunity for opportunistic screening,^{26,27} when men do seek care, several researchers have suggested that men receive more early cancer detection tests than women in the same practices.²⁸

Beyond patient age and gender, a patient's insurance status has been noted to have a consistently strong effect on the receipt of both early cancer detection and treatment services.^{29,30} For example, patients without private insurance have been noted to receive surgery for nonsmall cell lung carcinoma less often than privately insured patients,³¹ and the rates of bone marrow transplantation for the treatment of

patients with leukemia or lymphoma are 34-50% lower for self-pay and Medicaid patients compared with privately insured patients.³²

In the past decade, Medicare has extended benefits to include cervical, breast, prostate, and colorectal cancer screening; costs of antiemetic drugs used as part of cancer chemotherapy; Group C cancer drugs (investigational drugs monitored by the National Cancer Institute); and off-label use of certain drugs for cancer therapy. However, Medicare alone has not been sufficient to remove barriers to care.^{33,34} For example, Blustein³⁴ noted that, among Medicare beneficiaries, poor women and women with no supplemental insurance were less likely to have a claim for mammography than higher income women with supplemental coverage, suggesting that copayments and deductibles represented a substantial barrier to care for disadvantaged elderly women. In 1998, Medicare eliminated copayments and deductibles for mammography and extended benefits to include annual screening.^{35,36} It will be important to confirm that the additional benefits diminish financial barriers.

Although strategies to remove economic barriers, such as providing expanded Medicare benefits, will improve access to cancer care, recent research demonstrates that this is a necessary but not sufficient condition to improve cancer outcomes.^{33,37} For instance, recent studies of cancer screening and outcomes in Canada³⁸ and Finland³⁹ demonstrate that, despite universal access to care, individuals in lower social classes persist in having lower screening and survival rates⁴⁰ compared with individuals in higher social classes.

Beyond insurance inequalities,⁴¹⁻⁴⁸ an individual's social class appears to be an important independent barrier to care. For example, regardless of the measures used and the settings examined, patients in lower social classes consistently have lower breast cancer-specific survival compared with those in higher social classes.^{48,49} Hazard ratios for survival may be as much as 60% lower for breast carcinoma patients in lower classes compared with their more economically advantaged counterparts.⁵⁰ A similar pattern is observed for patients with multiple myeloma,⁵¹ lung carcinoma, and prostate carcinoma.⁵²

For some cancers, the observed survival disadvantage may be attributable largely to the use of screening and the disease stage at the time diagnosis, in which patients in lower classes are more likely to have their disease diagnosed at advanced stages compared with their more advantaged counterparts.^{1,28,52-55} For instance, women in lower social classes are more likely to report lower use of mammography and present at later stages of breast carcinoma than their more so-

cioeconomically advantaged counterparts.^{52,55} Patient delay in reporting symptoms does not appear to have a major effect on survival for individuals in lower social classes,^{50,56,57} although others have suggested that delay leads to poorer survival, largely mediated through stage differences at diagnosis.⁵⁸ However, even within stages of breast carcinoma, there are social class differences in survival,⁵⁹ suggesting that adequacy of staging evaluation (Lash and Silliman, personal communication), access to timely treatment, and host factors also may contribute to the observed class disparities in survival.^{60–62} Regardless of the treatment received, when cancer progresses, social class influences access to palliative and supportive care, with patients in lower classes reporting poorer symptom control and lower use of hospice care compared with patients in higher classes.⁶³

Although poorer cancer outcomes frequently are associated with nonwhite race,^{52,53} disentangling the effects of social class and race on patient outcome is complicated.^{64,65} For example, research on disease stage at the time of diagnosis,⁶⁶ rates of breast-conserving surgery⁶⁷ or other treatments, and breast cancer^{68,69} and prostate cancer⁷⁰ survival rates has demonstrated that race effects decrease or disappear after considering income or education. Another confounder of race and social class effects on access is insurance status, with minorities represented disproportionately among the uninsured or underinsured: Thirty-five percent of Hispanics and 25% of blacks report being uninsured compared with <10% of whites.⁷¹

Individual characteristics, such as race and ethnicity, are not inherently barriers to cancer care.⁷² Race is a composite term encompassing historic, biologic, sociocultural, and environmental factors, including exposure to racism.^{4,73,74} Thus, minority status may compromise access through cultural attitudes and perceptions of the care system or poverty. For instance, some Latino^{75,76} and African-American⁷⁷ populations have been noted to hold certain fatalistic attitudes toward cancer or to focus on day-to-day survival to the exclusion of seeking needed early detection or treatment care.^{27,73,78–81}

Such perspectives are likely to contribute to the observations that the rates of use of mammography, including regular use, by African-American and Hispanic women remain significantly lower than rates among nonminority women.^{82–89} Hispanic women report the lowest rates of Papanicolaou (Pap) smears or mammograms,^{87,90–93} although racial gaps in rates of recent screening may be diminishing.⁹⁴ Once African-American women and other minority women are screened, if they have an abnormal result, then as

many as 30–50% do not receive timely (or any) diagnostic resolution.^{95–98}

When African-American patients and other minority patients are diagnosed with cancer, even after considering social class, they are more likely to be diagnosed at advanced stages of disease than whites;^{28,52,96,99,100} for cervical carcinoma, this racial gap has increased over time despite greater use of Pap smears among African-American women compared with white women.¹⁰⁰

African-American patients and older minority patients also have been observed to receive suboptimal cancer treatment^{62,101–114} and to have lower survival rates when controlling for treatment, disease stage, tumor characteristics, and/or molecular markers of prognosis.^{52,98,115–124} For instance, black women have been noted to receive definitive local or systemic treatment for breast carcinoma less often than white women,^{101,111} and black men also have been observed to receive less intensive treatment for bladder or prostate carcinoma¹⁰⁸ and have higher prostate carcinoma recurrence¹²⁵ and death rates¹²⁶ compared with white men after considering other potential confounding variables. Furthermore, a recent Institute of Medicine report concluded that minorities still are under-represented in clinical research.¹¹⁴

Another group of patient barriers to cancer services includes the distrust of health care profession,^{87,127} lower levels of health literacy, language and cultural barriers, and fears and misconceptions about cancer.^{62,75,76,87,101–105,128–142} For instance, in a study of men with prostate carcinoma, black men were more likely to have metastatic disease at diagnosis. When lower levels of health literacy were considered, as measured by items such as comprehension of medication directions, race was no longer a predictor of disease stage at diagnosis.¹⁴¹

Beliefs that religious faith is an alternative to medical care also can act as a barrier to needed care.²⁷ Cultural beliefs also have been suggested as an additional mediator for poor race-related cancer outcomes. In a seminal article, Lannin and colleagues¹⁴² examined the predictors of a later disease stage at diagnosis for women with breast carcinoma. African-American race was associated significantly with having later disease stages at diagnosis (odds ratio [OR], 3.0; 95% confidence interval [95% CI], 1.9–4.7), although this effect diminished after controlling for socioeconomic status (OR, 1.8; 95% CI, 1.1–3.2). Most striking was the finding that, after considering cultural beliefs (such as folk beliefs, religious beliefs, relationships with men, fatalism, beliefs about treatment, and knowledge), the race effect was no longer significant (OR, 1.2; 95% CI, 0.6–2.5).¹⁴² Another explanation for

the findings by Lannin et al. is that black patients and other minorities experience unique barriers, such as discrimination when seeking care, that affect attitudes.^{28,143-145}

Across all patient groups, knowledge deficits, negative attitudes, and erroneous beliefs about cancer can act as additional barriers to access to early cancer detection or treatment services.^{54,146-154} For instance, beliefs that "nothing is wrong" if there are no symptoms also can be barriers to screening^{85,155} and, when abnormal results are noted, to compliance with follow-up recommendations.¹⁵⁶ In one study, women without symptoms were more likely to fail to follow up on an abnormal mammogram than women who had a palpable mass or other symptoms.¹⁵⁶ Even when symptoms are present, many individuals state that they prefer not to know whether they have cancer.¹

In addition to the patient demographic factors and attributes and beliefs depicted in Figure 1, our model posits that the social, economic, cultural context of family, neighborhood, and geographic locale also influence how individuals perceive symptoms and seek (or do not seek) health care and what resources will be available when they do pursue care.^{27,54,158-164} For instance, despite diminished access to cancer care, an individual from a lower social class group may live in a cultural context, such as Seventh Day Adventist, that promotes healthy behaviors, which, in turn, decrease the risk of cancer occurrence and poor cancer outcomes.⁷³ In contrast, living in a socioeconomically deprived area with high unemployment and crime¹⁶⁵ also can lead to a life view focused on day-to-day survival and can lead to lower cancer screening or later disease stages of breast, cervical, or colorectal carcinoma at diagnosis.^{28,53} Area resources also can affect access. For instance, Mandelblatt and colleagues⁶⁶ noted that living in a neighborhood with a high mammography capacity increased the odds of being diagnosed with local diseases compared with living in an area with a low mammography capacity.

Primary Care and Cancer Care Providers

In our conceptual framework (Fig. 1), in addition to patient factors, health care providers play a pivotal role in ensuring access to cancer care for their patient populations. In the section below, we briefly review several physician-related barriers to care. Because primary care and oncology providers generally face similar barriers to providing cancer care in their respective practices, and because there is a paucity of research on barriers specific to oncology practitioners, we summarize barriers for both groups.

Provider recommendations are one of the most con-

sistent predictors of receipt of cancer early detection and other services.^{19,54,87,88,130,166-170} However, investigators report several barriers to providing such services, including biases and beliefs about screening and treatment efficacy, deficient knowledge and training,¹⁷¹ lack of culturally sensitive resources,^{27,72,91,172} lack of time and forgetfulness,^{173,174} concern with patient's acute illnesses, lack of confidence (e.g., in clinical breast examination [CBE] proficiency),¹⁷⁵⁻¹⁷⁷ confusion about conflicting professional recommendations on standards of care,^{173,178,179} concerns about patient acceptance,^{173,180,181} lack of reimbursement or cost concerns,^{65,69,174,177,180-182} and logistic or organizational barriers.^{173-175,183} Physicians also may hold age or race biases. For instance, many studies have noted that physicians order mammography screening less often for elderly patients compared with younger patients.¹⁸⁴⁻¹⁸⁸ Providers also tend to order fewer intensive diagnostic work-ups¹⁸⁹ and offer definitive primary^{23,102,105,190-195} and adjuvant cancer treatment less often,^{103,104,106,111} including bone marrow transplantation¹⁹⁶ and radiation or chemotherapy after breast conservation,^{105,106} among elderly patients compared with younger patients. Beyond age biases, these patterns in management of the elderly may reflect the need to tailor therapy based on comorbidity, concerns about treatment toxicity, or differences in expectations of outcome among elderly patients and their physicians.

Subtle race biases of physicians also have been suggested as an explanation for the undertreatment of certain patient groups.¹¹¹ For example, several researchers have noted that physicians are more likely to order cancer screening for their white patients than for their nonwhite patients.^{87,88,112,128}

Physician characteristics, such as male gender,^{138,171,175,197} older age,^{171,198} white race,^{199,200} specialty practice,^{167,171,184,186,198,201-207} and a greater number of years since graduation²⁰³ all have been noted to constitute additional potential barriers to optimal cancer screening and treatment services. For instance, male physicians often perform cervical cancer screening less often than female physicians,¹³⁸ and they see patients for health maintenance visits less frequently than female physicians.²⁰⁷ Other examples include specialists who, when providing primary care, omit cancer screening more frequently than primary care providers.^{174,177}

Finally, as depicted in our conceptual framework (Fig. 1), physician-patient communication is another key domain in determining access to care. The quality of physician communication about cancer care has been noted to vary by physician gender,²⁰⁸⁻²¹² by patient race or ethnicity,^{87,209,211,213} and by patient social class.²¹⁴ For example, physicians discuss mammogra-

phy less often with their Hispanic patients than with their non-Hispanic patients, and Black patients are less likely to report advice about cancer screening than whites who see the same physician.¹²⁷ This will be an important area for further study and intervention.

Medical Cancer Care Environment

The last domain in our model represents attributes of the health care system within which patients and providers operate. Beyond specific patient or physician factors, system attributes can either facilitate or hinder obtaining needed care for cancer services (Fig. 1). Potential system barriers include organizational and structural factors, reimbursement and financial forces, quality measurement, and regional resources.

Over the past decade, hospitals and other health care systems have experienced unprecedented financial constraints with high rates of closings, relocations, mergers, and development of for-profit models.²⁹ The loss of care resulting from such closures or restructuring of financial eligibility requirements has been noted to have a strong adverse effect on chronic disease health outcomes, ranging from hypertensive control to avoidable mortality.^{183,215–217} The effects on cancer care are likely to parallel these trends.

In the same time period, another dramatic change in the structure of the health care system has been the rapidly increasing proportion of the U.S. population enrolled in managed care organizations.²¹⁸ However, there are few data available on how the structure and financing of managed care organizations affect access to and outcomes of cancer care.^{124,219–225} Although prior research demonstrates that managed care settings deliver more early cancer detection services than fee-for-service practices, even after attempting to account for self-selection factors,^{167,226,227} it is not clear whether patients of lower social classes, minorities, and elderly persons more recently enrolled in Medicaid or Medicare managed care will realize similar advantages.^{72,228} Once a patient develops cancer, the effects of the setting of care are conflicting. For instance, Lee-Feldstein and colleagues²²⁹ found that women who underwent treatment for local stage breast carcinoma in health maintenance organization (HMO) hospitals had poorer survival when controlling for patient age, tumor size, lymph node status, and histologic type compared with women who underwent treatment in large community and teaching hospitals.²²⁹ In contrast, Potosky and colleagues²²⁴ failed to find such an effect in two geographic settings; in fact, in one setting, women who were treated in HMOs had better survival compared with women who were treated in other settings.

The selection of physicians into managed care also may influence access to services. In a recent population-based study of California physicians, Bindman and colleagues²³⁰ found that physicians who cared for a larger percentage of uninsured and nonwhite patients were significantly less likely to have managed care contracts. Thus, the correlation between the organization and financing of care and cancer processes and outcomes are far from clear at this point and may be changing over time as the managed care market matures.

Other structural aspects of care, including hospital type and size, teaching status,^{110,231} and availability of radiation therapy,¹⁹⁴ influence access to care and the type of care received. For instance, women with local breast carcinoma who receive care in teaching hospital settings are more likely to receive breast conservation than women who receive care in nonteaching settings.^{110,223,232} Patients who are seen in larger practices also are more likely to be seen for health maintenance visits.²⁰⁷ Within a given health care structure, inadequate tracking mechanisms (e.g., identification of patients who miss appointments for screening, follow-up, or episodes of treatment) also can constitute a barrier to care.²³³

Regardless of the organization of care, the structure and process of primary and specialty care also can act to facilitate or impede the receipt of cancer services. For instance, among women with a regular source of care, Bindman and colleagues¹⁶⁹ noted that several features of optimal primary care, including availability of care, continuity, comprehensiveness, and communication, were related significantly to the receipt of breast and cervical cancer screening independent of insurance status, patient sociodemographics, and chronic disease history.

Financial structure and reimbursement variability also can act as barriers to cancer care. For example, in the fee-for-service sector, Medicare and Medicaid often reimburse providers less than private insurers for similar services,²³⁴ potentially acting to discourage providers or institutions from accepting patients with public insurance. Managed care capitation rates or financial incentives also may influence provider behavior if provision of extensive cancer services may result in a loss of income. The higher relative reimbursement for performing invasive procedures compared with providing patient counseling may act as a barrier to patient-physician communication.

Neighborhood health care resources, such as the number of mammography facilities per female population⁵² or HMO market share,²³⁵ have been noted to influence breast cancer stage at diagnosis or screening patterns. Finally, men and women in rural areas also

may be less likely to receive cancer screening or state-of-the-art treatment as a result of inadequate resources, long distances to sites of care, or transportation problems.²³⁶⁻²³⁸ For instance, regional variations in access to care have been noted, including differences in access to surgical treatment, for patients with breast carcinoma^{10,193,239-241} and prostate carcinoma.¹⁰⁸ The rates of use of systemic chemotherapy also show geographic variations, with patients in rural areas receiving less systemic treatment than those living in more urban locations.²⁴⁰

CONCLUSIONS

There are pervasive patient, physician, and health care system barriers to accessing quality cancer care. The central barriers that act at the patient level include low social class, minority status, and patient age; class and culturally mediated attitudes may be key final pathways that mediate the disproportionately poor cancer outcomes observed in these vulnerable population groups. At the physician level, gaps in training in patient-physician communication constitute an unaddressed barrier to cancer care. The growth of managed care represents the major potential system barrier or facilitator to better access to care: It remains to be seen which of these will result.

Many interventions to improve access to cancer services have been developed targeting one or more of the domains portrayed in our model of access to care. The majority of interventions focus on patient barriers to breast and cervical cancer screening. For instance, educational strategies based on a theoretical framework, such as the precede-proceed or predisposing, enabling, and reinforcing models of behavior, have been used successfully to overcome low patient knowledge or attitudinal barriers and to increase mammography screening rates.²⁴² Similarly, interventions targeted to physicians that rely on behavioral cues (e.g., reminders) and education have been used to increase breast cancer screening rates.²⁴³ There are few interventions that specifically target the elderly²⁴⁴⁻²⁴⁶ or racial minorities²⁴⁶⁻²⁴⁹ or that evaluate methods for improving colorectal cancer screening.^{250,251} To date, there also is a paucity of research on patient-based or physician-based interventions focused on cancer treatment or posttreatment care and fewer still that involve the medical care system. Interventions designed to enhance access also will need to be evaluated systematically to ensure that patient outcomes are improved in the most cost-efficient manner. Together, future interventions hold the promise of eliminating the current inequalities in access to cancer care in the United States.

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