Minority groups with diverse racial and ethnic heritages and persons living in poverty are much more likely to die of asthma and to require emergency care for exacerbations of asthma than white persons not living in poverty. The National Heart, Lung, and Blood Institute convened a multidisciplinary group of expert scientists and clinicians to review current research aimed at understanding risk factors for these disparities in asthma health outcomes, to describe key barriers to improving asthma outcomes, and to establish priorities for future research. Education programs for asthma and other chronic diseases were reviewed. Successful elements of clinic and community-based programs were identified. Factors potentially involved in producing disparities include gene-environment interaction, psychologic and social factors, and socioeconomic status. Stress potentially contributes to asthma morbidity at both the individual and community level. Recommendations are made to stimulate research to understand risk factors for disparities and their mechanisms (eg, gene-by-environment interactions and the role of stress), to define appropriate research designs and methods for evaluating behavioral and community interventions, and to examine how differential access to care contributes to morbidity. Research is encouraged to identify strategies that improve cultural adaptation and adoption of proven programs in a variety of populations. (J Allergy Clin Immunol 2002;109:229-37.)

**Key words:** Minorities, asthma, disparity, outcome

In the United States minority groups with diverse racial and ethnic heritages experience disparities in asthma care that result in differentially high morbidity and mortality. African Americans are 3 times more likely to be hospitalized and 4 times more likely to die from asthma. Increasing information is becoming available indicating that morbidity and mortality from asthma is also high in US Hispanic populations, particularly Hispanics from Puerto Rico. For example, in New York City the average annual rate of hospitalization was 62.9 per 10,000 among Hispanics, 59.9 among African Americans, and 12.2 among whites. Hispanic residents of New York City had a higher annual mortality (1.3 per 100,000) than among non-Hispanic whites (0.4 per 100,000).

In general, morbidity from asthma is higher in urban populations. In urban African American children this increase in asthma morbidity parallels overall poor outcomes from health problems. Prominent among issues resulting in increased morbidity from asthma is the absence of regular care. Urban children experience more difficulty managing their asthma for a variety of reasons, including poverty, stresses of living in an urban area, lack of family and community support, and lack of knowledge of asthma and its treatment.

The National Heart, Lung, and Blood Institute convened a multidisciplinary group of expert scientists and clinicians for a 1 1/2-day workshop with the goals of reviewing current research aimed at understanding risk factors for the disparities in asthma health outcomes that are experienced by minority populations and persons living in poverty and describing key barriers to improving asthma outcomes. A major outcome of the workshop was identifying promising opportunities for research and research translation aimed at overcoming barriers and reducing disparities in asthma outcomes.
LESSONS FROM APPROACHES TO CHRONIC DISEASE IN MINORITY COMMUNITIES

Education of patients about asthma management

A number of randomized trials have demonstrated that education about asthma and encouragement for self-management substantially reduces the risk of emergency department visits, hospitalizations, and lost days of work when compared with usual care. Characteristics of effective programs are (1) teaching patients to self-monitor, (2) giving patients a written treatment plan that allows self-adjustment of medications, and (3) offering or providing regular appointments to review the progress of care. Patient education is most effective when linked closely to clinical care, especially when this care has a preventative focus. Program efficacy has been most convincingly demonstrated for programs targeting adults, but there is considerable evidence that asthma self-management programs can be effective with children.

Although there is consensus that self-management skills are valuable, there is no definitive knowledge about which of the broad range of skills taught are most important and which components of asthma-education programs promote these skills most effectively. With regard to disparities in asthma outcomes encountered by minorities, asthma-education programs can be equally successful in minority and majority populations. Strategies used in asthma-education programs for minorities that appear to be important in their success include presentation in the language of the community, use of methods appropriate for people with low literacy skills, and use of needs assessment and learner-centered teaching methods to access concerns of program participants. The greatest problem in reaching minority populations is not lack of effectiveness but lack of understanding about how to establish patient programs in different settings and how to encourage patients to become engaged in the education process.

There has been considerable research on the education of physicians about asthma management. There is evidence that following key recommendations in clinical practice guidelines for appropriate pharmacologic therapy and for patient education reduces hospitalization rates substantially. Most methods used to promote use of asthma guidelines by physicians, as with general continuing medical education, have had limited success. However, there is encouraging evidence that interactive learning by small groups of physicians and problem-based learning and feedback on care provided through practice profiling can affect significant change. The issue is not whether there are effective methods of improving asthma outcomes through physician education but how to introduce and sustain effective physician education programs in the larger health care system. Forming regional alliances with managed-care organizations serving minority populations may create opportunities for studies to test more widespread implementation of physician education.

Development of programs to improve both patient and physician education must take into account health care beliefs and attitudes about the seriousness of asthma and the possibility of controlling it. This is true both for the patient and the health care provider. The clinician’s ability to address his or her patients’ beliefs can augment the capacity to diagnose and manage asthma in accordance with practice guidelines. For example, a program designed to improve physicians’ communication skills, emphasizing the need to elicit and address patient concerns, results in improved asthma outcomes.

Evaluation of approaches to other chronic diseases

Asthma is only one of many health conditions in which there are disparities in care and outcome among minority populations and persons living in poverty. Over the past 2 decades, substantial research has explored community approaches to cardiovascular risk reduction and diabetes management. One objective of community-based programs is to include larger numbers of individuals, especially currently healthy adults and children who may not be reached through clinical channels but who are at risk for development of disease. The results of many of these programs have been modest or disappointing, in part because development of interventions by investigators often prevents audience members from having a substantial role in program governance and does not offer flexible implementation to suit local needs and preferences. Programs that have emphasized local authority in program direction have achieved significant community-wide effects in smoking cessation, as well as in asthma outcomes. Interventions in hypertension care and control and childhood obesity prevention have also indicated the importance of multiple and flexible interventions in producing favorable outcomes.

Elements of successful community programs in diverse settings

There is diversity in beliefs and practices that are based on culture, social class, education, and minority status, all of which interact and contribute to health disparities. Beliefs and practices affect both the type of program likely to be effective and the research conducted in a community to develop and test interventions. Cultural beliefs and practices form a significant part of a patient’s approach to health and wellness, with individual patients combining personal, cultural, and biomedical beliefs and practices and suggesting individual approaches. Use of traditional complementary and alternative medicine approaches may be powerful in many communities and should be taken into account in programs and research. Approaches to care must include obtaining a health-beliefs history and asking about folk, home, and alternative therapies being used. Combining traditional biomedical treatment with alternative therapy may be the most effective approach to delivery of care for the patient by integrating biomedical treatments into cultural beliefs. Most cultural practices are internally logical and consi-
tent. Synthesis and negotiation between medical and patient-held beliefs and practices can be successful.38

Successful community intervention programs have drawn on areas of strength within minority communities rather than solely addressing deficiencies to help implement health-behavior change programs. Successful programs have taken advantage of communities with strong extended-family ties and community involvement, a traditional heritage of strength and wellness, healthful native foods, cultural sharing and family cohesion, and a high valuation of children. The involvement of the community is crucial for program success.

Research needs to focus not only on the behavior of individuals but also on the multiple social forces within the environment that shape and support individual behavior both positively and negatively. For example, research is needed to identify how cultural beliefs and practices influence health-seeking behaviors and how interventions can build on these influences to maximize behavior change. Improving access to care must thus include approaches not only to resolving problems in the structure of health care delivery but also to addressing psychologic issues and beliefs and practices within the culture.

Research in minority communities should disaggregate the effects of contextual factors, such as culture, social class, and minority status. These variables contribute separately and interactively to disparities in care and outcome of chronic diseases. Likewise, traditionally used racial and ethnic descriptors (eg, non-Hispanic black, Hispanic, and white) often lump groups together that have different epidemiologic, social, and cultural profiles.39 Differences in acculturation also account for intragroup variations in chronic illness prevalence, as well as approaches to health, illness, prevention, and treatment.40 Sensitivity to these contextual variables is essential to providing high-quality research, health education, and clinical care.

Successful community-based research to reduce the risk of chronic disease among minority populations appears to have common themes. These include building academic-community partnerships, maximizing community participation, creating and maintaining a community advisory board that participates in all aspects of the research, employing and training indigenous community workers, integrating the study into the life of the community, locating the study office in the community, using academic investigators as resources to the community, and providing technical assistance in areas not always related to the study. Involving students from local colleges or universities in a study may help build sustainable health programs. Intervention teams must be multidisciplinary and include community health workers to provide outreach services. Motivated staff is an important factor in both study completion and producing effects. Patient incentives are very important for initial recruitment and ongoing retention.

An important lesson of previous community health interventions is that considerable time is needed to develop a strong trusting relationship between minority communities and academic institutions. Seed grants are probably needed to build the relationships with communities and to develop the infrastructure necessary before grants are written or certainly before interventions are begun. Development of instruments that are applicable to the culture involved in the intervention, in addition to being valid and reliable for the collection of the research data, is part of this process of building relationships. Availability of culturally valid research instruments is particularly important when designing interventions for diverse cultural groups or when there is a limited knowledge base on effective models for intervention. Communities are more responsive when there is trust and involvement from known and respected community members. Training, education, and mentoring of local staff members will extend the benefits of the program beyond the life of the grant. Outcomes of treatment studies in the area of reduction in treatment seeking for acute myocardial infarction indicate that traditional approaches seem to work as well in minority as in nonminority populations but only with significant attempts to involve the active participation of community members.41,42 Multicomponent studies seem to offer promise for producing the greatest gains and affecting broader societal segments involving working with community members to organize the community in support of the intervention, with providers to better incorporate methods to educate patients with targeted patient education materials, and broad-scale community education efforts to enlist the support of unidentified patients and the community at large.41

RESEARCH ISSUES ON CAUSATIVE FACTORS PRODUCING DISPARITIES

Gene-environment interaction

Asthma is a heritable trait, but genetic factors alone cannot explain the rise in asthma prevalence, morbidity, or mortality.43 However, a small change in the prevalence of relevant environmental exposures could explain a significant rise in disease prevalence among genetically susceptible individuals.44 Gene-environment interaction, defined as the coparticipation of genetic and environmental factors,45,46 is particularly relevant to the cause of asthma morbidity in racial-ethnic minorities because these groups experience a disproportionate burden of environmental exposures that influence asthma morbidity.47 Relevant exposures include smoking, stress, nutritional factors, infections, allergens, and occupational exposures. In addition, racial-ethnic variability in the distribution of genetic polymorphisms can potentially modify the response to pharmacotherapeutic agents.48,49 For example, the prevalence of functional polymorphisms in the gene encoding β2-adrenergic receptor varies across race48,49; it is unknown, however, whether pharmacogenetic differences contribute to disparities.50 Moreover, obesity occurs disproportionately in US minority populations50,51 and increases the risk for asthma.52 A genetic polymorphism in the β2-adrenergic receptor has been
Multiple factors exist that potentially influence asthma morbidity. Both exposure and response to these factors can be measured quantitatively to identify both pathogenetic and protective mechanisms that contribute to asthma severity and health care use. Exposure to psychologic and social stressors occurs either at single points in time or at multiple points with cumulative effects. The level of exposure to stress can be assessed through measures of the types of stressors, the variability within stressors, and the focus of stressors. It is possible to assess the duration and timing of psychosocial exposures (i.e., whether they are acute or chronic and whether they have the most effect during periods of vulnerability). In addition, the psychologic, behavioral, and physiologic response to stress and perceived stressfulness can be assessed, not only in individuals with asthma but also in members of the individual’s social network, including children, parents, and siblings. Assessment of stressors for members of the social network should include the same domains as for the individual of interest.

**Socioeconomic status**

SES refers to the level of access persons have to resources, as well as their relative status within prestige-based hierarchies. SES has 3 main components: education, occupational prestige, and income (including indicators of wealth and poverty). Alternative indicators exist for each component, and each indicator (e.g., highest degree obtained, maternal education, wealth, home-auto ownership, material hardship, ratio of income to needs, changes in economic status, community characteristics, and timing of material deprivation) has specific advantages and disadvantages. Studies of a hypothesized effect of SES on disparities should incorporate measures of SES at multiple levels (individual, household, and neighborhood). It is also important to incorporate such measures at different points in the life course because there may be temporally defined (e.g., early childhood vs adolescence) windows of susceptibility to the effects of SES. There is a need for studies of intervening mechanisms to enable interpretation of contemporary associations of race and SES with health. At the same time, however, those studies may have limited application beyond the specific setting in which they were conducted because of historical and contextual differences in the mechanisms that link SES and race to health. SES and race should be viewed as fundamental social causative factors that contribute to disparities through access to resources, avoidance of risks, and minimization of the consequences of disease. The specific risks and stressors that are implicated in their relationships with health may change over time.

**Other methodological issues**

As reviewed in the workshop, causative factors contributing to observed social and racial-ethnic disparities in asthma include genetic polymorphisms, cultural practices, psychologic adjustment, stress-related biologic factors, variations in exposures to allergens, and socioeconomic conditions. Such factors influence asthma rates.
both independently and jointly, so that research designs to study cause must have the ability to test possible interaction effects. For example, the role of stress in the cause and exacerbation of asthma may involve interactions between immune, neuroendocrine, and behavioral factors. In addition, immunologic sensitivity is thought to interact with exposure to allergens to influence asthma outcome. Another example of possible interaction effects is illustrated by the increase in asthma rates among inner-city children and young adults, which may reflect the joint occurrence of both urban living and higher levels of stress. Selection of appropriate study designs to test such effects is critical. If resources permit a prospective cohort design, investigators may want to use a stratified sampling procedure to include individuals with various combinations of risks, such as urban children with and without socioeconomic adversity or individuals representing different ethnic groups with varying levels of environmental exposures.

A second methodological issue that frequently plagues causative research studies is the confusion of individual risk factors with conditions that determine group differences in asthma rates. This has been referred to as a Type III error or getting the right answer to the wrong question. This occurs when (1) individual risk factors do contribute to the likelihood of a person developing asthma but do not contribute to group differences in asthma rates or (2) the causes of interindividual differences interact with the causes of group differences to create the current asthma rates. This kind of error can pose problems in the effectiveness of interventions, which may be effective in reducing individual risk but have no effect on disparities in asthma rates.

RETHINKING THE FRAMEWORK OF ASTHMA CARE

Various strategies can improve asthma management, including asthma-education interventions focused on building patient self-efficacy and self-management skills, diagnostic and treatment support, and use of specialty services. In addition, system performance measurement and more complex strategies, such as case-management interventions and disease-management programs, have been and continue to be tested. These differing types of health care delivery strategies have begun to form the foundation for more complex interventions.

The chronic-care model is an approach for improving asthma care. This model is based on the theory that asthma is one of many chronic conditions the care of which depends on complex multiprovider and multisystem support systems. Central to this approach is the perspective that the patients should be assisted to view their condition as one in which disease control, rather than cure, is the goal, and self-management is a critical component of successful therapy. The chronic care model integrates medical-care system and social-support system intervention, as integral components of a larger, comprehensive intervention. Studies of this model in the care of the frail elderly and patients with diabetes have proven successful. Evaluations of the chronic-care model in asthma programs, through comprehensive case-management systems and quality-improvement programs, are currently under way. The question remains as to how cost-effective the chronic care model is in helping integrate the complex care needs of minorities and low SES populations who are at greatest risk for unnecessary asthma-related morbidity and mortality.

Disparities in quality of care, defined as “the degree to which health services for individuals and populations increase the likelihood of desired patient outcomes given the current state of knowledge . . . ,” likely contribute to disparities in asthma outcomes. The quality-improvement approach uses a systematic program to improve care, either through reduction of medical errors and variability in practice or through innovation. In this context care is the product of the system that produced it. Thus various components of the health care system are potential targets for quality-improvement strategies, including the broad environmental context of patient care: the organizational environment, defined microsystems (eg, a clinic), patients-consumers, and the community. Delineation of these components permits formulation of testable hypotheses on which approaches to quality improvement (eg, focus on organization and its leadership vs focus on the role of data) can be associated with changes in care and outcomes in different settings. Although it is likely that efforts to improve quality will likely result in changes in care, significant questions remain as to what specific approaches are most likely to help reduce disparities in asthma care and in what settings.

EVALUATION DESIGNS FOR COMMUNITY-BASED BEHAVIOR-CHANGE INTERVENTIONS

Because disparity in the outcome of asthma care is a public health problem, approaches to reduce disparities are often studied at a community level. Such approaches are complex and ever changing, operating on multiple levels with multiple strategies and often changing as community members work together. Research on community-based behavior-change interventions should not only identify ways to improve asthma care but should also increase understanding of the processes associated with program success (eg, description of programs and policies developed by the intervention and the program’s ability to address issues that matter to the local community itself). Data required in community evaluation can be gathered across a broad range of community subgroups involved in the intervention, and multiple goals of asthma care and control need to be included. Changes in asthma outcomes can be assessed with data from health care delivery systems, schools-employers, insurers, ongoing vital and health statistic systems, and patients and families.

Randomized clinical trials are a powerful test of causality but may be infeasible for study of complex systems or multilayered interventions, such as those delivered on a community-wide basis. Most difficult is that
factors that are not manipulated over time. In fact, evaluation of previous community-organization programs using conventional research designs may have led to underestimation of the potential of community-organization programs to change health outcome. Alternative designs for approaching questions of effectiveness of community organization programs include the following:

1. reversal and multiple baseline designs in which all who are studied are offered different treatments as part of a central research plan;
2. sequential analysis of achievement of program objectives and implementation, audience engagement effect, and outcomes relative to data-based criteria;
3. multivariant modeling of the effects of the dose of treatment amidst control variables and individual- or community-level background variables; and
4. once overall effect is proven, research should focus on evaluating the relative importance of separate program components rather than overall program effect.

RECOMMENDATIONS

Fundamental research to advance understanding of disparities in asthma outcomes

Definition of risk factors underlying disparity. Although asthma is a heritable trait, it is unlikely that genetic factors alone explain either the rise in asthma prevalence or the disparities in outcome. However, gene-by-environment interactions likely play a role in determining disease severity and possibly prevalence. Two fundamental environmental areas, psychologic and social factors, as well as physical environment, were discussed, and their interactions were considered. Psychosocial factors, such as stress, depression, cultural beliefs, and discrimination, often track with physical environmental issues, such as exposure to irritants and allergens in poor housing stock and the presence of crowding and multiple caregivers. There are studies evaluating the roles of many of these factors. However, the interaction between different factors, such as stress-depression and irritants-allergens, needs study to determine final common pathways in producing disparity.

Stress is emerging as a major area for further study. Issues needing study include the importance of stress at individual, family, and community levels; the differential roles of exposure and perception of exposure; and possibly the timing or trajectory of stress (ie, whether a critical period for a single trauma or a persistent high level of stress is necessary to produce an adverse effect). Other questions include the contributions of family-social roles to the generation and reaction to stress, whether the effect of stress on asthma is different than on other diseases, and whether different types of stressors affect asthma than affect other diseases.

Studies to design and evaluate interventions. Although there have been a number of studies and advances in the area of quality of life, development of instruments specifically to address quality of life in minority and low-literacy populations could facilitate research and understanding of outcomes. Similarly, although many advances have been made in the area of patient education, the mechanisms to effectively reach different populations need to be expanded and defined.

Components of therapeutic regimens and patient-education strategies to promote successful outcomes differ depending on the target audience and perhaps even on individuals within audiences. There is a need to define this variability, particularly because regimens and programs need to be adapted culturally for specific groups. Two general issues for intervention were discussed, one at a provider level (patients often do not get the best care) and a second at the personal-community level (patients cannot use effectively the best care when it is offered). In both these areas there is need for study of the role-advantage of giving choices among alternative interventions to test strategies to change behavior at both the provider and individual level, to study the integration of complementary alternative medicine into more traditional care, and to study interactions and attempts to change systems as opposed to only changing individual behavior. Studies of the role of social support in change are needed. There is a need to involve the target communities in both research and behavior change.

Study of how differential access to care contributes to morbidity. Although it seems apparent that differential access to care contributes to morbidity, the specific roles of cultural perceptions of risk and prioritization of illness and seeking care need definition. There is a need to better characterize attributes of access that contribute to successful care. Research might be carried out to test different approaches to partnerships that would link hospital and medical system–based programs to community organizations that serve homeless, migrant worker, and immigrant populations.

Identify most suitable outcome measures. The traditional outcomes used to evaluate asthma interventions (ie, asthma hospitalizations and emergency department visits) are still relevant but need to be supplemented by measures of intermediate outcomes, such as the extent of engagement of a community in planning and executing the intervention, to evaluate programs and processes. These intermediate outcomes must be sensitive to multicultural settings and be common to studies across different sites to permit comparisons among different interventions. Cost-effectiveness needs to be included in program evaluation. The social effect of disease must also be measured.

Research to identify strategies for dissemination and diffusion of ideas on reducing disparity

Although fundamental research is needed to advance the understanding of disparity, considerable knowledge is already available. One challenge has been to disseminate currently available knowledge into models of care that will improve disparities in asthma outcomes. Changes both in systems and individual physician practice need to be further evaluated. Systems for considera-
tion would include all aspects of providing asthma care. Specific issues could include scheduling appointments, monitoring patients’ pulmonary function and symptom status between visits, ensuring easy access to medication and medication-delivery devices, and insuring that the entire clinic staff intervenes with the patients to link medical care to the home and work environments. Comparison between community organization strategies with hospital-based outreach programs may be important as a way to identify the best pathways and strategies for dissemination-diffusion and institutionalization of best practices. The role of financing redesign was considered, as was the development of programs in conjunction with approaches to other chronic diseases.

Research to improve application (dissemination) of interventions to defined populations

Experience with many health problems has shown the importance of working with the community and involving its members in deciding which issues are to be addressed and how programs should be designed. Time to establish the infrastructure for requisite communication needs to be built into intervention trials. Although each individual community requires somewhat different approaches, there is a need to evaluate interventions across communities and thus a need to develop core elements and evaluation systems that can be used in a number of different settings. It is possible that intensive efforts tailored to the needs of and directed exclusively to specifically defined groups at risk of high asthma morbidity are necessary to reduce disparities in outcomes, rather than taking a more general approach to improving care for all. For example, several different programs tailored to patients from different ethnic groups who are treated at a particular emergency department more than twice in 1 year may be more beneficial than a general community program. Research is needed to test this possibility and to link program outcomes to specific reductions in disparities.

Cooperative research centers

Cooperative centers of research that foster partnerships among minority-serving institutions (MSIs), research-intensive institutions, and the communities in which asthmatic patients live accelerate development of our capacity to improve health outcomes among minority and economically disadvantaged populations. In these centers a 2-way partnership for research would be promoted in which (1) research-intensive institutions will be stimulated to get involved in research on reducing disparities and will be guided by the MSI on how to conduct such research in a culturally sensitive manner that promotes community participation and (2) the MSI will be mentored by the research-intensive institution to help build its resources, capacity, and skills to conduct research that merits National Institutes of Health support. A sustained partnership is envisioned in which the collaborators will prepare joint investigator-initiated proposals and will exchange training opportunities over the long term. Collaborative research would be promoted in a combination of research areas, such as epidemiology, pathophysiological mechanisms, pharmacogenetics, clinical trials, complementary and alternative medicine, or education (for patients or health care professionals) aimed at elucidating and ameliorating disparities in prevalence, effective treatment, and management of asthma among minority and economically disadvantaged populations. The cooperative centers would also identify a career-development program that expands the scientific cadre of investigators dedicated to research on asthma in minority populations.

REFERENCES


APPENDIX

Workshop participants: Robert C. Strunk, MD (cochair); Jean G. Ford, MD (cochair); Lee Bone, RN, MPH; Randy Brown, MD; Carmen Chavez; Edith Chen, PhD; Noreen Clark, PhD; Michelle Cloutier, MD; David Evans, PhD; Edwin Fisher, PhD; Charles Homer, MD, MPH; Augusto Litonjua, MD, MPH; Floyd Malveaux, MD, PhD; Diane McLean, PhD, MPH; Jane McLeod, PhD, MPH; Lee Pachter, DO; James Raczynski, PhD; Cynthia Rand, PhD; Virginia Rauh, PhD; Mary Story, PhD; Virginia Taggart, MPH; Kevin Weiss, MD; Sandra Wilson, PhD

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