

Improving Health Care Efficiency: Strategic Approaches to Managing Care for Asthma, Sickle Cell Disease and Tuberculosis *Conference Proceedings*

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A Great Cities Institute Working Paper



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The Great Cities Institute

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Introduction

On May 2, 1995 the University of Illinois at Chicago's Great Cities Initiative, in collaboration with Bethany Hospital in Chicago, a member of the Advocate group of hospitals, brought together local policy makers, researchers, health care providers and consumers in an all-day working conference on the effective and efficient management of sickle cell disease (SCD), asthma and tuberculosis (TB). Management of these three diseases is a major health problem facing state and local governments as they attempt to move the Medicaid population into a capitated system.

Some health care providers propose that such conditions, which are costly and often difficult to control, be exempt from capitated models of health care. However, participants in this conference recommended that these three conditions can best be treated within a Medicaid capitated system if it allows for adequate provider and client education; service coordination among the health care, school and community systems; alternative models of health care delivery; and other specialty referral services. A successful Medicaid capitated system would reduce unnecessary medical costs, such as repeated diagnostic tests, improve health outcomes and reduce the public's risk of contracting communicable diseases such as TB.

Through panel presentations followed by open discussion, participating stakeholders considered the following five points for each disease:

1. What is known about effective management of the disease?
2. What are the gaps in knowledge about managing the disease?
3. What actions are necessary to implement effective disease management?
4. What costs/barriers are involved in implementing effective disease management?
5. What is the effect of allowing the limitations imposed by cost barriers to result in failure to take action?

Conference participants identified strategies likely to have an impact upon the management of these diseases among vulnerable populations dependent on Medicaid. Although further research is needed to test the efficacy of each strategy and to consider its policy implications, several may merit trials by health care systems bidding for Medicaid managed contracts. A summary of each panel presentation, the general discussion following it, and some potential policy implications follow.

Sickle Cell Disease (SCD)

Panel chair **Mabel Koshy, M.D.**, an internist and director of the Sickle Cell Clinic at the University of Illinois Medical Center, presented the following background information on SCD in the United States:

Approximately 72,000 Americans have SCD. Of this number, an estimated 4,000 live in Illinois, 3,000 of them in the Chicago metropolitan area. The total cost for hospitalization in the State of Illinois for 1992 and 1993 was \$100 million.

A chronic blood disorder, SCD results from a genetic anomaly that produces abnormal hemoglobin in red blood cells and primarily affects black populations in the United States. In contrast to normal red blood cells, the faulty cells become sickled when deoxygenated. As a result of this, patients with SCD live with episodic, unpredictable and oftentimes complicated painful crises that can lead to multi-organ damage. These painful crises may be associated with increased stress, hypoxia, infection and/or dehydration and may last from a few hours to several days.

In 1972, Congress mandated and allocated funding through the National Heart, Lung, and Blood Institute for the development of ten Comprehensive Sickle Cell Centers (CSCC). The purpose of these centers is to conduct clinical and basic research and to provide patient and family education aimed at improving the overall quality of patient care. Basic research conducted over several decades has led to the elucidation of the pathogenesis of SCD at a molecular, cellular and clinical level. Clinical research has helped document its clinical course. Both clinical and basic research have led to intervention strategies, including mandatory newborn screening, treatment, and prevention as well as management of acute episodes of pain. One outcome of this research has been the discovery that use of the drug hydroxyurea can decrease the frequency of painful crises in SCD.

Despite the ongoing research, SCD continues to be a drain on the health care system and to frustrate providers and consumers. In 1993, a total of \$58 million was spent on health care for SCD patients in Illinois. Of this total, 82 percent was paid for by the Illinois Department of Public Aid and by Medicare. Current goals are to reduce acute episodes, which may decrease the number of emergency department visits and hospital admissions, and to improve the quality and efficiency of care, which will enhance the quality of life for persons with SCD.

Karen O'Mara, M.D., director of Critical Care at Resurrection Hospital and an emergency medicine physician, reviewed the objective of emergency department care and its inability to deliver ongoing patient care for SCD:

Historically, the objective of emergency department care is to address life-threatening conditions with the goal of either stabilizing or admitting the patient. Such care is not oriented to prevention, early intervention or follow-up. However, some emergency departments are the only source of medical care for an underinsured or uninsured patient.

Emergency departments are often staffed with rotating physicians. Sometimes these physicians work for private corporations that contract with the hospital to run the emergency department facility. In such instances, the physicians' accountability lies with the corporation, not the hospital.

Emergency department physicians may not have access to a patient's medical history and/or a patient may be a poor historian. Hence, there are intrinsic barriers created by emergency department objectives and staffing patterns coupled with patient behaviors and expectations that lead to fragmented and expensive care.

The course of disease for patients with SCD can vary from asymptomatic to severely ill with multiple crises and multiple organ damage. A mild painful crisis may be managed at home with hydration and oral analgesics, while a moderate to severe crisis may require a day treatment center, emergency care and/or hospitalization. However, many patients and providers do not have sufficient knowledge about managing SCD. This often leads to frequent use of the emergency department, increased hospitalizations, and iatrogenic complications, which are more costly than preventive care.

Between 1992 and 1993, emergency visits for SCD in three Chicago medical centers increased. Hospital admissions, 80 percent of which were for uncomplicated pain, likewise increased. The three hospitals then met and developed guidelines for managing uncomplicated, painful SCD crises. The guidelines were tested in two hospitals; the third served as a control. Six months later the data revealed 95 percent physician compliance, a 25 percent decrease in emergency department visits, a 20 percent decrease in hospital admissions, and a 15 percent increase in outpatient clinic visits.

Currently, the guidelines are being tested in other Chicago area hospitals. The goal is to encourage emergency department physicians to adhere to the guidelines in order to decrease hospital admissions, assist the patient in coping with a tolerable level of pain, improve patient and provider accountability and decrease catastrophic complications.

Bea Barber, MA, CSW, a licensed and certified clinical social worker with 15 years of experience counseling persons with SCD and their families, discussed psychosocial, transcultural and economic issues relevant to managing SCD:

Education of physicians, patients, families, schools and communities is the best strategy for implementing effective management of SCD. Physicians need to understand the effective management of uncomplicated pain and SCD in general, have access to patient information, and be aware of cultural or religious norms that may complicate the patient's treatment. Patients need to understand the importance of primary care for their disease so they can gain control over their lives, make informed decisions and be held accountable for follow-up. This assumes that the patient has access to primary care.

Families require education and emotional support. The family is often the only caregiver for the person with SCD, and family roles may change as a result.

School systems can play an active role in providing vocational training, which may lead to employment and economic independence. For example, children and young adolescents should be encouraged to pursue more sedentary careers that would be less likely to precipitate a crisis and potential unemployment.

Community resources are often underutilized either because the patient is unaware of them or the patient's provider may not understand how the patient can access helpful community resources.

Louise Dorn, RN, a clinical nurse specialist who has worked with Dr. Koshy for more than 15 years, concluded the panel portion with her comments:

At least 75 percent of emergency department visits by patients with SCD are due to painful crises. For the patient with SCD, pain is unpredictable and recurrent, and the effects are cumulative, i.e., each painful crisis causes some vascular occlusion that damages vital organs.

Barriers to adequate pain relief include: provider disbelief of the patient's complaint, limited access to care, lack of provider knowledge about managing uncomplicated pain, and lack of provider and patient accountability.

Strategies aimed at improving the quality and efficiency of care include:

1. standardizing medical management through patient and provider education;
2. creating a computerized registry, or Sickle Cell Disease Resource and Information System, that includes the daily treatment, hemoglobin genotype, past medical history, baseline laboratory data, blood bank data (phenotype), and radiographic results for patients with SCD;
3. developing a day treatment center to manage uncomplicated pain; and
4. creating a comprehensive ambulatory care center to provide total patient care, serve as a resource and help develop collaborative research projects through which a strong patient-provider partnership can emerge. These interventions will reduce crisis-oriented treatment and use of expensive emergency department facilities.

Discussion

A person living with SCD initiated the open-floor discussion. She made the important point that because she wanted to maintain the level of care she had been receiving from Dr. Koshy, she felt she had to continue to see Dr. Koshy even though these visits were not covered by her HMO. *She did not seem to know how to access information that might help her find a provider covered by her HMO who might be using Dr. Koshy's protocol.* If in fact no other providers in her HMO offer this care, it illustrates the need either for more providers with access to the protocol or education of insurers about the benefits of management by centers using the protocol. Either way, third-party payers are clearly another group that could benefit from education about the cost-effectiveness of management of SCD using the hydroxyurea protocol.

Other points of interest were these:

- Stakeholder groups need to continue to examine the pros and cons of implementing a sickle cell disease registry. For example, there are trade-offs between protecting patient confidentiality (which has not been a problem with tracking infants identified through mandatory cord screening) and providing better provider access to information about a patient wherever the patient enters the health care delivery system.
- Managed care may or may not restrict access to needed services or reduce cost by eliminating "unnecessary" services. A particular concern brought up throughout the conference was whether patient education would be included as an eligible service under managed care.
- Patients should have a role in quality assurance. It was recommended that patients be educated about how to assess whether they are receiving "adequate" care.
- Establishing a Comprehensive Sickle Cell Center in Chicago should be an important objective.
- Implementing guidelines for managing uncomplicated, painful SCD crises throughout Illinois is an important way to reduce the costs of managing this disease.

Policy Questions

The panel presentation and open-floor discussion stimulated at least five questions that have policy implications. Further practice-based research is needed to answer these questions, understand the policy implications and offer policy recommendations.

1. Can patients with SCD and other chronic diseases receive comprehensive care under a Medicaid managed care system? (Benjamin, et. al., 1993; Burdick, 1994; Hughes, et. al., 1993; Mauldon, et. al., 1994; Rowland and Salganicoff, 1994).
2. What impact would a Sickle Cell Disease Resource and Information System have on the cost and effectiveness of managing SCD? Could it reduce the need for diagnostic testing and aid in preventing or minimizing catastrophic complications? (unpublished, Koshy, Dom and O'Mara, 1995).
3. What are the critical factors that lead to frequent emergency department care for SCD patients? (Hand, et. al, 1995; Yang, et. al., 1995).
4. Would implementing guidelines for managing uncomplicated painful crises reduce the cost of treating persons with SCD in the State of Illinois? (unpublished, Koshy, Dom and O'Mara, 1995).
5. How can community health resources be redesigned to educate and support people living with chronic disease such as SCD? (Brindis, et. al., 1995; Brown and Hanis, 1995; Eng and Smith, 1995; Luepker, 1994; Rieger and Henderson-Smart, 1995)

Asthma

Panel chair **Victoria Persky, M.D.**, an internist at Erie Family Health Center and an epidemiologist at the University of Illinois at Chicago, School of Public Health, opened the discussion with a brief presentation focusing on morbidity and mortality trends in asthma.

Asthma is one of the most common and costly pediatric disorders in the United States. According to 1989 data from the National Heart, Lung and Blood Institute, 9-12 million people in the United States have asthma. Of persons receiving Aid to Families and Dependent Children (AFDC) funds in Illinois, 43 percent have this disease.

Despite the prevalence of asthma and its debilitating effects, it is a poorly understood disease. The National Institutes of Health in 1994 characterized asthma as a lung disease constituted by airway obstruction, airway inflammation, and airway hyper-responsiveness and ranging from mild to severe.

Nationally, the total overall costs for asthma in 1990 exceeded \$6.2 billion dollars (Weiss and Budetti, 1993); the total estimated direct costs in 1990 exceeded \$3.5 billion dollars (ibid.). About \$713 million is spent annually on medications alone.

During the mid-1970s through the 1980s, asthma-related deaths decreased. Since the mid-1980s, asthma-related deaths have increased again, with a disproportionate part of that increase occurring in the African-American population. Targonski and colleagues (1994) used death certificate data to examine mortality rates among African-Americans and whites aged 5-35 in Chicago from 1968 through 1991. They found that asthma mortality did not significantly change among whites but increased by 337 percent among African-Americans. The largest increase was in young African-American adults between ages 20-34. The largest increase in asthma-related hospitalizations was in African-American children.

Factors affecting mortality trends in asthma include: access to care, changes in pharmacological therapy, indoor and outdoor allergens and genetics. Access to care is of special importance because African-Americans and individuals from lower socioeconomic backgrounds often encounter financial difficulties that limit their access to care and reduce the likelihood that they will receive appropriate primary care.

James Olsen, M.D., a pediatrician at Erie Family Health Center, has been treating inner-city children for five years. He examined the management of asthma from the provider's perspective.

The goals of managing asthmatic patients are to: reduce school absenteeism; encourage as normal a life as possible by allowing the patient to participate in activities with their friends, to sleep comfortably, and to reduce hospital stays; and reduce the direct (treatment-related) costs of asthma.

As with SCD, education plays a key role in managing asthma. Parents and patients need to understand the basic pathophysiology of the disease, including

the early signs and symptoms, and how to reduce environmental factors that trigger acute episodes. Health care providers must be able to identify symptoms of asthma, keep abreast of current treatment modalities, and be aware of problems in the home environment that may trigger acute events and interfere with the treatment regime.

However, education is costly and time-consuming for both parents and providers; as a result, these factors become barriers to effectively managing the asthmatic. Another barrier is a child's inability to self-administer his/her medication at school because public school policy requires a school nurse to administer the medication and not every school has a full-time nurse. Schools must work with parents and providers, therefore, to deal with this problem.

Janelle Tucker shared her experience with the health care system as a parent of an asthmatic child and in the process illustrated the importance of clear and consistent patient and family education.

Originally, Ms. Tucker thought her daughter had a cold, so she took her to the emergency department. The emergency department physician diagnosed her daughter's condition as asthma, treated her and sent her home. Ms. Tucker was under the impression that the asthma would be resolved with medication and that her daughter would outgrow it. She was unaware of the disease process and the need for constant monitoring and consistent contact with a primary care physician.

Later attempts by emergency department staff to explain asthma and its effects on her child's current and future well being were inadequate because they spoke about asthma using complex medical terms. It was not until a staff member took the time to explain the seriousness of asthma to Ms. Tucker in terms she could understand that she could appreciate the need for consistent care and monitoring.

Michael McDermott, M.D., co-director of the adult asthma clinic at Cook County Hospital, addressed such barriers as managed care, financial problems faced by patients, and organizational barriers from a policy perspective.

The overall atmosphere for managing diseases like asthma through Medicaid appears to be "gloomy." Historically, managed care has been a system driven by cost-reduction, and it has not encouraged patient education and research. Consequently, policy makers must recognize the implications for patient education and research of shifting from a Medicaid fee-for-service to a managed care environment.

To date, there is no standard protocol for managing asthma. Additional research is required to achieve a protocol that is effective while reducing long-term costs of treatment. For example, the management of asthma can be improved by promoting the use of inhaled steroids and peak-flow meters. These therapies have proven to be cost effective but are underutilized. One reason is that managed care protocols do not include standard guidelines for managing asthma with inhaled steroids. Research could focus on how to operationalize guidelines

and to incorporate procedures that would reduce cost and improve quality of care.

Financial barriers also prevent patients from seeking primary care and following prescribed treatments. Many health care plans require co-payments and deductibles that can be significant obstacles to seeking care. Management of the disease often requires ancillary equipment and frequent visits to the doctor, which may not be possible given financial constraints. The result may be episodic health care, increased emergency department visits and more frequent or prolonged hospitalizations.

Major organizational barriers in the managed care environment are limited reimbursement for patient education and unrealistic standards for determining the appropriateness of outpatient versus inpatient care. Initially, newly diagnosed asthma patients require frequent monitoring and education, but once they are stabilized and educated about their disease, they use fewer services. Major questions are who will provide the education and who will pay for it. A statewide education program may be beneficial wherein patients are taught about their disease and how to assess their quality of care. Currently, standards of care are measured by the number of outpatient visits and hospitalizations rather than by quality. Within a managed care environment, methods should be developed to change patient and provider behaviors.

Discussion

Discussion points include the following:

- Patient education requires that information provided be clear, consistent and culturally sensitive, so patients and parents can understand the disease process.
- Community health advocates can help form partnerships between younger and older asthmatics and experienced and inexperienced patients which might reinforce education and disseminate information that already exists in the community.
- Educating primary care providers in managed care settings about the importance of early diagnosis and treatment of asthma may reduce the number of referrals. Training ancillary personnel to help with patient education would free up physician time. Shifting the focus of patient management from the primary care physician to the patient or the parents would empower them to manage their own cases.

Policy Questions

The following six questions were aimed at improving the quality and management of asthma with special attention to a managed care environment:

1. What is the most cost-efficient and effective manner to disseminate information on asthma and educate health care consumers? (Butz, et. al., 1994; Clark, Gotsch and Rosenstock, 1993; Denson-Lino, et. al, 1993; Krahn, 1994; Marion, Creer and Reynolds, 1985; Thapar, 1994)
2. Would implementing standard of care guidelines improve the quality of care for

patients with asthma? (Hesse, 1995)

3. What role would consumer advisory groups play in monitoring the quality of care for patients with chronic diseases such as asthma? (Fisher, et. al., 1994)
4. What role do peer educators have in prevention and management of asthma? (Spinetta and Collins, 1993)
5. What is the feasibility of allowing children in the public school system to self administer medication? (Fitzgerald, et. al., 1993)
6. Does institutional coordination, e.g., between schools, health care providers, families and communities, affect the treatment and management of asthma? (Lewis, Schwartz and Ianacone, 1988; Skaff, 1988)

Tuberculosis

William White, Ph.D., professor of economics at the University of Illinois at Chicago and Associate Director of the Institute for Government and Public Affairs at the University of Illinois at Chicago, chaired the panel.

Becky Wurtz, M.D., an infectious disease specialist at Cook County Hospital, outlined the historical trends of Tuberculosis (TB), an infectious disease caused by a bacterium that affects the pulmonary system and that, if left untreated, may spread to bones and other organs.

Between 1900 and 1985, reported cases of TB in the United States consistently declined. They began to rise again in 1987, especially in large urban counties and specifically the inner cities.

Some primary determinants of the rise in TB cases are the increase in HIV-infected persons, the increase in immigration to the United States from high TB-prevalence regions of the world, the increase in use of congregate living facilities (i.e., shelters, nursing homes, public housing, halfway houses and jails) and the deterioration of the medical infrastructure set up to diagnose and treat TB.

Socioeconomic status is an important risk factor for TB -- specifically, as income declines, the risk of TB increases. Between 1985 and 1992, TB in African American and Hispanic populations increased in all age groups (most prominently in young adults), whereas in the Caucasian population the increase was significantly smaller, and TB incidence actually declined in some age groups.

Completion of TB treatment is difficult because people with TB tend to be transient and because current treatment facilities are not designed to maintain successful contact with these populations.

William Trainor, M.D., an infectious disease specialist at Cook County Hospital, discussed the system of treating TB patients at Cook County Hospital, where approximately 24 percent of cases in Chicago are diagnosed and treated each year without the involvement of the Chicago Department of Public Health. The hospital's TB treatment completion rate is approximately 60

percent.

There are two main problems in managing tuberculosis cases at Cook County Hospital and in general. The first is a shortage of beds in the isolation ward. All patients with suspected TB are admitted to the isolation ward, which currently has 36 beds. For every five patients admitted, one is diagnosed with infectious TB. The average length of stay on the isolation ward for a person with suspected TB who eventually tests negative is seven days. The average stay for a person with suspected TB who eventually tests positive is 14 days.

The second problem is an ineffective discharge procedure combined with the transient nature of the TB population. This impedes the long-term physician/patient relationship that is necessary to ensure treatment completion.

Cook County Hospital is currently testing a procedure that may make TB diagnosis more efficient at the facility. An isolation team of pulmonologists evaluates all persons with suspected TB in the emergency ward. If suspicions remain, the patient is admitted to the isolation ward, where he or she is seen by the sputum induction service. This involves the daily evaluation of all isolation ward patients by a respiratory therapist. After three consecutive days of negative sputum tests, a patient is recommended for discharge and subsequent outpatient treatment. This procedure has reduced unnecessary in-patient days on the isolation ward.

Three other possible strategies might improve the efficiency of TB treatment: 1) creating more isolation beds at Cook County Hospital, 2) improving communication among public and private medical facilities in order to monitor completion of treatment, and 3) creating temporary housing for homeless patients to facilitate more efficient monitoring of therapy.

Antonio David Jimenez, an ethnographer for the Community Outreach and Intervention Project (COIP) of the School of Public Health at the University of Illinois, discussed preliminary findings of a collaborative project between COIP and the Chicago Department of Health (CDOH). In cooperation with the CDOH, COIP recently created a pilot program for implementing direct observed therapy (DOT) for TB patients within the drug-using population.

Three factors complicating treatment of TB in injectable drug-users (IDUs) and in other substance abusers are: (1) a high level of addiction to illicit drugs or a drug "habit," (2) the drug-seeking lifestyle of a drug-user, and (3) the stigma associated with having TB.

Persons with high levels of addiction are more concerned with the needs of their addiction than their health, so TB treatment becomes secondary. The increased availability of more potent drugs has contributed to this situation; one example is the popularity of "rocks," or crack cocaine, a drug that almost always is smoked. Persons addicted to crack cocaine may go on a "smoking run" for several days and congregate in smokehouses. Because they share pipes and because the process by which individuals smoke crack (inhaling deeply, and holding the smoke for as long as possible) produces a cough, these smoke houses become

environments ripe for TB transmission.

Secondly, the transient lifestyle of heavy drug-users or IDUs creates great difficulty in contacting them and monitoring their therapy. The IDU's transient lifestyle often is linked to: having to find a reliable drug supply, pooling money with others to rent a room, having no money and depending on others for a place to sleep and keep belongings, or sharing space in an abandoned building. This lifestyle and substandard housing may also facilitate the transmission of TB.

Finally, the stigma attached to TB puts the known TB patient at risk of being evicted from group housing arrangements and increases the likelihood of being excluded from drug-sharing groups. Thus, the addicted TB patient will be unlikely to risk disclosure that he/she has the disease, making treatment and follow-up difficult.

William Paul, M.D., Medical Director of the Chicago Department of Health's Communicable Disease Center, commented on the current situation in Chicago regarding TB. One problem is that although most TB testing currently is done on school-age children, they are the least likely group to be infected with TB.

The primary difficulties are in tracking TB cases and in inducing patients to complete treatment. The completion of treatment is necessary to avoid the increase of drug-resistant strains of TB resulting from sporadic drug therapy, among other reasons. The most successful means of ensuring treatment completion is DOT, but more resources are needed to increase DOT in Chicago. Furthermore, the controversy of who will pay for DOT needs to be addressed, specifically in terms of Medicaid and third party insurance coverage.

The Chicago Department of Health needs the cooperation of local hospitals and medical professionals to maintain a database of information on all TB patients. Such a database would enable more efficient tracking of transient patients as well as enhance follow-up contact for outpatient therapy.

Discussion

In open-floor discussion, four key points surfaced: 1) the problem of tracking patients throughout treatment, 2) the shifting of patient costs from private insurance companies to public clinics, 3) the lack of knowledge of appropriate therapy by physicians who see few TB patients, and 4) the need to increase the availability of DOT. At the core of these four points is the question of how to assure that patients diagnosed with TB complete treatment. One approach to this question is to examine specific problems associated with three types of providers:

- Primary care providers who have infrequent experience with TB patients do not understand the course of pharmacological interventions. Therefore, a critical issue is provider education.
- Primary care providers who frequently see TB patients in the course of treating them for other health problems and who understand pharmacological intervention may lack special provisions for treating them. The issue is whether or not to build an internal mechanism to coordinate care or refer patients to sub-specialists.

- Pulmonary and infectious disease specialists who work in TB clinics, understand treatment issues, and have a coordinated treatment approach may treat a transient population, e.g., the homeless. Here, the issue becomes the possible redesigning of the health care system to accommodate special populations that require temporary housing arrangements.

Policy Questions

The panel presentations and open-floor discussion stimulated four research questions that have policy implications. Tuberculosis is a public health, i.e., societal responsibility and a reportable communicable disease. Therefore, policy questions must reflect the fact that successful TB therapy benefits not only the patient but society as well.

1. Can coordinating public and private health-care delivery systems improve the efficiency of the tracking and surveillance of TB cases? (Moody, 1995; Steimke, et. al., McCormick, 1994)
2. How can the health care system increase the capacity to deliver DOT? (Villarino, Geiter and Simone, 1992; Winters, 1994)
3. Does the dissemination of information about TB prevention and treatment to primary care physicians and other health care providers, patients and families reduce the incidence of TB and/or improve TB therapy completion? (Bellin, Fletcher and Safyer, 1993; Canadian Thoracic Society, 1994; Winters, 1994)
4. Would temporary housing for transient TB patients increase therapy completion? (Collins, 1989--unpublished document; Concato and Rom, 1994)

Summary

As a result of panel presentations and discussions on the effective and efficient management of SCD, asthma and TB, policy questions were framed related to the three diseases in the context of managed care and Medicaid managed care. Recent figures indicate that 51 percent of all people are enrolled in some type of managed care plan (Gabel, et. al., 1993) and, as of June 1994, all but seven states reported having at least one Medicaid managed care program (HCFA, 1994). In 1993, less than 10 percent of Illinois' Medicaid beneficiaries were enrolled in a Medicaid managed care program (HCFA, 1993), but Illinois hopes to increase this percentage.

Various studies (Benjamin, et. al., 1993; Goodman, 1995; Mauldon, et. al., 1994; Miller and Luft, 1994; Newacheck, et. al., 1995; Rowland and Saliganicoff, 1994) reveal that the ability of Medicaid managed care plans to improve access to health care and to reduce cost varies among populations. Inherent in this shift from a fee-for-service delivery system to a managed care system are imperatives for conducting policy research to examine the impact of primary care on quality of care, to determine what elements of primary care are most important in decreasing costs related to emergency department visits and hospitalizations, and to evaluate the efficacy of alternative models of care (Alexander and Clancy, 1994; Clancy, personal communication, May 2, 1995; Clancy, Gold and Wall, 1993; Inglehart, 1994).

The policy questions formulated by participants in this conference with respect to managed care

and Medicaid managed care were concentrated in four sub-groups: (1) access to care, (2) accountability, (3) access to education and information, and 4) organizational transformation, e.g., utilization of alternative and creative models of health care delivery.

Access to Care

Access to care has a different meaning for persons with SCD or asthma and persons with TB. For patients with SCD or asthma, poor access to care implies that they do not seek/receive care because they are underinsured or uninsured, have high co-payments and deductibles, or lack knowledge about the importance of continuity of care. Although persons with TB may not access health care for similar reasons, the situation is made worse by the fact that TB is an infectious disease that, if untreated, can spread. Moreover, the population infected with TB is transient, making it difficult to ensure therapy completion.

Examples of policy questions posed in the context of access to care are:

- Can patients with a chronic disease receive comprehensive care under a managed care system?
- Would temporary housing for transient TB patients increase therapy completion and access to care?

Accountability

In the past, patients with SCD or asthma were primarily seen by specialists, and TB patients were seen primarily in public health clinics. Managed care settings emphasize primary care and cost containment (which implies the rationing of referrals to sub-specialists). Thus, the health care system requires methods to ensure that providers in managed care settings deliver quality patient care.

Examples of policy questions posed in the context of accountability are:

- Would implementing standards of care for the treatment of SCD, asthma and TB reduce emergency department visits, hospitalizations, and iatrogenic complications?
- Would implementing provider certification programs ensure quality care in a Medicaid managed care setting?
- What role could consumer advisory groups or coalitions play in monitoring the quality of care for these diseases under a Medicaid managed care system?

Access to Education and Information

This policy area deals with the best methods of disseminating information to ensure that emergency department physicians have access to pertinent patient information, that primary care physicians are familiar with current treatment guidelines, and that public and private health care systems share knowledge to enhance tracking and surveillance of TB patients.

Examples of questions are:

- Who is responsible for ensuring that primary care physicians in Medicaid and other managed

care settings have the knowledge to manage these diseases?

- How can community settings be designed to disseminate information and reinforce patient education?
- Would a sickle cell disease registry reduce the number of hospital admissions and complications?
- Does greater patient knowledge decrease emergency department visits and hospitalizations?
- Can coordinating the public and private health care systems improve the official tracking and surveillance of TB patients?

Organizational Transformation

With the implementation and expansion of Medicaid managed care programs comes the opportunity for stakeholders to collaborate and create more efficient ways of delivering health care to persons with SCD, asthma and TB. Perhaps Medicaid managed care and managed care plans can create partnerships with alternative systems in order to deliver care to special populations.

Policy questions include:

- What is the feasibility of allowing children to self-administer medication in school?
- How can the public health system increase its capacity to deliver DOT?
- What are the non-traditional settings in which patients with SCD, asthma and TB can receive care?
- At the heart of the conference presentations, discussions, and policy questions is the potential for reducing health care costs and improving the quality of care in a Medicaid managed care setting for vulnerable populations. These goals may be achieved through service coordination, provider and consumer education, quality assurance, alternative treatment delivery systems and innovative methods for disseminating information and drug therapy. Finally, addressing the policy questions posed for asthma, SCD and TB management can lead to models of care that address service delivery for vulnerable populations in general.

Appendix

Panel Members

The following chairpersons and members of the sickle cell disease, asthma and tuberculosis panels provided expertise and guidance.

Sickle Cell Disease

Mabel Koshy, M.D., panel chair, internist and director, Sickle Cell Disease Clinic, University of Illinois Medical Center, Chicago

Bea Barber, MA, CSW, licensed and certified social worker, Marriage and Family Counseling Service, Office of the Chief Judge of the Circuit Court of Cook County, Chicago.

Louise Dorn, RN, clinical nurse specialist, Sickle Cell Disease Clinic, University of Illinois Medical Center, Chicago

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Asthma

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James Olsen, M.D., pediatrician, Erie Family Health Center, Chicago

Janelle Tucker, consumer and parent of an asthmatic child

Tuberculosis

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