Sickle Cell Anemia

As someone who has had a long-term commitment to research in the neglected sociological and health services aspects of sickle cell disease, I want to applaud you for the recent articles in the January/February 1997 issue of *Public Health Reports*. The three articles provided a rare but needed reminder to all of us in the public health community of the importance of a population-based approach to care. This is especially relevant given the problems that have been and will be created by health and welfare reform and the lack of support on the part of some providers and insurance sources for substantive changes in the care of people with chronic conditions, particularly people of color.

Given the nature of the recent articles and their clear call for further research in understanding the impact of access, economics, and utilization of health services for people with sickle cell disease, I was somewhat puzzled by Dr. Schecter's summary. After his thorough review of the research articles, he closed his summary by shifting focus back to the traditional biomedical and bioclinical approaches in highlighting support for new drug treatment and therapies. Did he miss his own point?

While there is absolutely no question that significant progress in drug and other therapies have improved the length and quality of life for people with sickle cell disease, at the same time the literature is also very clear that only a small number of people with these conditions (about 20%) utilize most of the resources targeted at sickle cell disease[1] and, tellingly, may be eligible to benefit from most new therapies.[2,3] As a result, about 80% or more of the population are, at any one time, asymptomatic and lead normal lives but have to deal with the ecological issues—for example, discrimination in jobs, access to life and health insurance, and stigmas associated with having an invisible chronic condition. We know little about this 80%; yet our failure to investigate them could constitute a vital missing opportunity to learn and apply important lessons about how such individuals manage their day-to-day lives.

Unfortunately, one of the main reasons for this situation has been the almost total absence of support for the study of these issues from the major Federal funding sources. This suggests a funding gap that could be addressed by the joint efforts of agencies focusing on health care delivery (such as HCFA or AHCPR) and the traditional source of funding for sickle cell research, the National Heart. Lung, and Blood Institute, to address the social and health services issues of this population, which are particularly linked to bioclinical and disease management issues.

There are signs that this situation may be changing, as evidenced by the mention of possible research on managed care in the recent Comprehensive Sickle Cell Disease Center Request for Applications. Yet from a public health perspective, and in light of the great biomedical and bioclinical successes, the lack of attention to primary and secondary prevention issues have and will continue to impede our reaching the promise of the goals embodied in the World Health Organization definition of health: improving the well-being of a population of physical, emotional, and social beings who happen to have sickle cell disease.

Sincerely,

JOSEPH TELFAIR, MSW/MPH DrPH
Assistant Professor
Department of Maternal and Child Health
University of Alabama at Birmingham

References

1. *See for example* Woods K, Karrison T, Kosby M, Patel A, Friedmann P, Cassel C. Hospital utilization patterns and costs for adult sickle cell patients in Illinois. Public Health Rep 1997; 112:44–51.
2. *See for example* Charache S, Terrin ML, Moore RD, Dover GJ, Barton RD, Eckert SV, et al. Effect of hyroxyurea on the frequency of painful crises in sickle cell anemia. NEJM 1995;332:1317–22.
3. *See for example* Platt OS, Guinan EC. Bone marrow transplantation in sickle cell anemia—the dilemma of choice. NEJM 1996;335:426–7.

Dr. Schechter Replies

Dr. Telfair makes a very important point. The advances of biomedical and bioclinical approaches will be of importance only if they are translated into improved care for the populations at risk for pathology. As a physician who has spent most of his professional career in basic and disease-oriented research, I was honored that *Public Health Reports* asked me to comment on the several articles on the care of sickle cell disease patients. I tried in my commentary to explicitly address *both* the public health and the biomedical research communities.

We must be careful not to allow the differing perspectives of these two professional communities to continue to divide us. Medical research has given us new therapies, including vitamins, hormone replacements, and antibiotics; vaccines; and now molecular genetic approaches to diagnosis and therapy. Research advances should continue to reduce the marginal costs of medical care and thus help us approach the WHO definition of health for larger and larger populations—if we work together.

ALAN N. SCHECHTER, MD
Chief, Laboratory of Chemical Biology
National Institute of Diabetes and
Digestive and Kidney Diseases
National Institutes of Health