



The Management of Sickle Cell Disease

U.S. Department of Health

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This book is B&W copy of the government agency publication. #1 Best Seller on Sickle Cell Disease. This edition of The Management of Sickle Cell Disease (SCD) is organized into four parts: Diagnosis and Counseling, Health Maintenance, Treatment of Acute and Chronic Complications, and Special Topics. The original intent was to incorporate evidence-based medicine into each chapter, but there was variation among evidence-level scales, and some authors felt recommendations could be made, based on accepted practice, without formal trials in this rare disorder. The best evidence still is represented by randomized, controlled trials (RCTs), but variations exist in their design, conduct, endpoints, and analyses. It should be emphasized that selected people enter a trial, and results should apply in practice specifically to populations with the same characteristics as those in the trial. Randomization is used to reduce imbalances between groups, but unexpected factors sometimes may confound analysis or interpretation. In addition, a trial may last only a short period of time, but long-term clinical implications may exist. Another issue is treatment variation, for example, a new pneumococcal vaccine developed after the trial, which has not been tested formally in a sickle cell population. Earlier trial results may be accepted, based on the assumption that the change is small. In some cases, RCTs cannot be done satisfactorily (e.g., for ethical reasons, an insufficient number of patients, or a lack of objective measures for sickle cell “crises”). Thus the bulk of clinical experience in SCD still remains in the moderately strong and weaker categories of evidence. Not everyone has an efficacious outcome in a clinical trial, and the frequency of adverse events, such as with long-term transfusion programs or hematopoietic transplants, might not be considered. Thus, an assessment of benefit-to-risk ratio should enter into translation of evidence levels into practice recommendations. A final issue is that there may be two alternative approaches that are competitive (e.g., transfusions and hydroxyurea). In this case the pros and cons of each course of treatment should be discussed with the patient.

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