

'Race', Health and Social Care

Series Editors: Waqar I.U. Ahmad and Charles Husband

NEW

THE POLITICS OF SICKLE CELL AND THALASSAEMIA

Elizabeth N. Anionwu and Karl Atkin

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"...a most interesting, eye-opening and often challenging book...it should be read by anyone involved in dealing with haemoglobinopathies, in the health or social care setting. Many others who are interested in the broader issues around chronic and particularly genetic disease will also find it stimulating reading." - Dr Anne Yardumian, Consultant Haematologist, North Middlesex Hospital, London

Sickle cell disorders and thalassaemia are inherited blood disorders. Sickle cell disorder alters the shape of the red blood cells from their usual round appearance to something which resembles a sickle, or half moon. Those born with thalassaemia major are unable to make a sufficient amount of haemoglobin. They will develop a fatal anaemia in early childhood if not treated with blood transfusion every four to six weeks, for life. Sickle cell disorders and thalassaemia are found mainly in families that come from Africa, South Asia, the Caribbean, the Eastern Mediterranean and the Middle East. There are estimated to be over 10,000 people with a sickle cell disorder (SCD) and around 600 cases of thalassaemia in the UK. Despite this high incidence, it is still an under researched topic, and a subject about which health professionals and policy makers know very little. After years of neglect, it is now attracting policy interest and there are new moves to improve existing provision.

This timely book examines the politics of sickle cell and thalassaemia and offers a detailed evaluation of the services available. It is unusual in placing patients and their families at the centre of the study, allowing their views to be heard, and relating them to the delivery and organization of services. The problems that emerge range from inadequate language support, inappropriate generalizations, poor quality care, as well as institutional and individual racism. The book also identifies models of good practice and suggests ways in which we can learn from these. General policy and practice issues are highlighted throughout, and the need for a more systematic approach to planning and providing culturally sensitive services is addressed.

Contents: The politics of sickle cell disorders and thalassaemia - Origins, geographic distribution, genetics and laboratory investigations - Clinical features and management - Genetic screening and counselling: ethics, politics and practice - The experience of sickle cell and thalassaemia - Health and social care provision - Past achievements and future strategies - Bibliography - Index.

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