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Screening and counselling for sickle cell disorders and thalassaemia: The experience of parents and health professionals

Karl Atkin a ... Elizabeth N Anionwu b

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Abstract

Shortfalls in haemoglobinopathy provision result in patients and their carers receiving inadequate support. This paper, by drawing on material from a project evaluating service provision to families caring for a child with a sickle cell disorder or thalassaemia, discusses screening and counselling services. It explores the perspectives of parents, front-line practitioners, managers and health commissioners. Poor quality care, inadequate information and professionals' insensitivity were salient themes in parental accounts. The parents' experience also confirms the problems faced by minority ethnic people in having their welfare needs recognised, more generally. Although our focus is on genetic conditions affecting minority communities in the UK, the issues we address are at the heart of the 'new genetics'.



Keywords

sickle cell disorders; thalassaemia; ethnic minorities; screening; counselling; genetic conditions

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