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Services for sickle cell disease: unified approach needed

Sickle cell disease is an autosomal recessive disorder affecting one in 30 blacks of Afro-Caribbean origin.¹ The prevalence of the carrier state is no less than twice that of cystic fibrosis in the white population.^{2,3} About the same number of people in the UK suffer from sickle cell disease as from haemophilia A (5000 (C Brown, Policy Studies Institute, London, unpublished observations)) and both the disease and asymptomatic carrier state can be easily detected by a blood test. Some 10-20% of people die from the disease in the first 10 years of life,^{4,5} and sufferers have a haemolytic anaemia and recurrent painful vaso-occlusive crises for all their lives.⁶ In later life renal failure and bone necrosis cause chronic disability. Time lost from school leads to poor educational achievement and high unemployment,⁷ and the economic and social cost to an already disadvantaged community is substantial.

The coordination of services for those with sickle cell disease—whether clinical, social, educational, or employment—requires a lead from the Department of Health and Social Security, supported by funding. The department, however, insists that this provision is a matter for district health authorities.⁸ The effect of this policy is apparent from a report, commissioned by the east London branch of the Sickle Cell Society, about services for sickle cell disease in the London Borough of Newham.⁹ This describes an almost total lack of facilities compounded by poor liaison among general practitioners, hospitals, and the community. Inadequate, or incorrect, and condescending advice seems to have been all that was available from health workers. Not surprisingly, the

black community perceives this paucity of services as racist, although it would seem familiar to the haemophiliac of 20 to 30 years ago.

Happily, things are improving in Newham, with clinics becoming organised and access to hospital being improved. But it remains difficult to convince health service administrators in general of the scale of the problem and of the need for established funding of educational, screening, and counselling services. "Support," but no money, is usually all that is forthcoming. A satisfactory solution to the medico-social problems of sickle cell disease could be achieved cheaply using the successful model of haemophilia care, and the scheme could operate under similar sponsorship by the Department of Health. Most of the requirements have already been identified.^{2,10}

In the districts the care of patients with sickle cell disease should be concentrated around a team, comprising the haematologist, paediatrician, and obstetrician, and together they would provide consistent management throughout the patient's life. General practitioners in areas of high incidence of the disease, identified as described in the Newham report, should receive specialised information and training.

Screening pregnant women from ethnic groups with a high incidence of haemoglobinopathies must be followed by testing the partners of carriers. Both antenatal diagnosis and selective abortion of affected pregnancies should then be offered to couples at risk. The Newham survey suggests that people are much more interested in antenatal diagnosis than has been thought.

Sickle cell counsellors have been of immense value in providing support and advice for patients and their families and education and screening for the community. They are also ideally placed to tackle educational and employment problems in both the school and the workplace. Probably one counsellor will be needed for every 50 sufferers and financial support is required urgently to establish these posts nationally.

Optimal management of sickle cell disease from the time of diagnosis at birth should help to reduce the morbidity and mortality in the early years of life,¹¹ as well as improving the educational and employment prospects later. Eventually, greater awareness in the black community may lead to a reduction in the number of new cases of sickle cell disease.

In some parts of the UK these results will be achieved because of the efforts of individuals. Nevertheless, to ensure that patients everywhere can obtain specialist care, advice, and support will require a unified approach sponsored by the Department of Health. This will have the additional benefit of showing that professed commitments to ethnic minority health care really have some substance.

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