Coping with sickle cell disease: a self help manual

Sickle cell disease (SCD) is a genetic condition resulting in the abnormal synthesis of haemoglobin, predominantly affecting Africans and Caribbeans, but also people from Asia, the Mediterranean region, and southern Europe. The hallmark manifestation of SCD is acute painful bone and muscle cramps resulting from the occlusion of blood vessels and tissue ischaemia, posing a great challenge in management. Other symptoms include damage to major organs such as the spleen, liver, kidneys, and lungs; and increased vulnerability to severe infections.

SCD causes much distress to affected children and families, impeding their daily lives. Thus, treatment should be directed towards improving quality of life. Self management interventions encourage acquisition of effective coping strategies to alleviate symptoms and achieve better quality of life. This approach seems attractive for SCD because children have to learn to cope daily with a chronic disease from an early age. Self help materials are now employed widely in the psychoeducational management of chronic diseases in childhood. These empower children to self manage their condition, and allow non-specialised staff and carers to offer appropriate support.

The Department of Health funded the development of a “Self Help Manual” for the psychological management of children with SCD. Children are introduced to the self help manual at 7 years of age in a paediatric cognitive behavioural therapy (CBT) programme. The manual comprises patient education (including information about SCD, pain, and management), cognitive therapy (dealing with thoughts and feelings), behaviour therapy (including activity scheduling and communication skills training), and relaxation. The manual can be downloaded from a website (www.sickle-psychology.com), which also offers further information relating to self management.

The self help manual presents children with SCD with an innovative and exciting approach to managing their condition in the community, and at their own pace. It also enables health professionals (including psychologists) to replicate brief CBT in a “child friendly” format, and offers researchers a valuable tool. Evaluation of the use of this self help manual in the Paediatric Psychology Service for SCD in northwest London is in progress.

K A Anie
Brent Sickle Cell and Thalassaemia Centre, Central Middlesex Hospital, Action Lane, London NW10 7NS, UK; kafi@sickle-psychology.com

References