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 pain in bones and muscles 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 or improvement 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.

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References

BOOK REVIEW

Paediatric Respiratory Examination


If there were an award for teaching material, this CD would win hands down. It is truly outstanding. That said, my heart sank when I was asked to review the disc because our last PC with a sound card had just been stolen. Preregistration house officers know about these things and have a lot of time on their hands. I asked John Saunders, our preregistration house officer in paediatrics, to find a suitable PC and show the CD to the undergraduates and SHO. The students thought it was “brilliant”. Here is his report.

This CD Rom has 50 minutes video and 100 minutes audio. It is for junior doctors, medical students, nurses, physiotherapists, GPs, and for use as a teaching aid.

Subjects taught are asthma, tracheostomy, pneumonia, bronchiolitis, stridor, bronchiolitis, examination, and the neonate. Drop down menus expand each subject into, for example, definitions, history, clinical examination, and clinical cases. A chance to hear narration expanding the concise text or accompanying the videos is present on most pages. Videos show clinical cases with excellent clinical signs. Clicking highlighted text brings up definitions with related narration and video. There is also a single page glossary with links for viewing at any time.

Students liked the uncluttered layout, finding it easy to navigate. They appreciated the many clinical signs demonstrated, many of which they had read about but not yet seen in their attachments. The audio prompts ensured that they did not miss the more important features. The glossary was particularly helpful for quick reference, when they did not have time to go through whole sections of the CD Rom. The sound production was of extremely high quality.

Junior doctors also found it useful for revision but would have found a reference page helpful. One senior paediatrician thought it was “brilliant”, especially as it endorsed her view that wheeze is difficult to appreciate without a stethoscope. We have been promised that there will be several copies of this in the library for us to look at before the next lecture.

S McKenzie