In a sickle-cell and thalassaemia centre

KOFI ANIE *describes how psychological interventions are integrated in a multidisciplinary approach to two serious blood disorders.*

IS there such a thing as a 'typical' day in my job? I hadn't thought about it until now – I wonder how you would describe your own.

I am a practitioner with a clinical health psychology role in a multidisciplinary team at the Brent Sickle Cell and Thalassaemia Centre, part of the Department of Haematology at Central Middlesex Hospital in London. My work portrays the increasing involvement of psychologists in managing patients in a medical setting.

Unsurprisingly, most psychologists know little about sickle-cell disease and thalassaemia, two inherited haematological conditions. Sickle-cell disease causes recurrent pain and the restriction of blood supply to tissue from the occlusion of small blood vessels by abnormally 'sickle-shaped' red blood cells. Other complications include damage to major organs such as the spleen, liver and lungs, and an increased risk of stroke in children. Thalassaemia is characterised by the absence or reduction in the production of haemoglobin, with variation from mild to severe anaemia. In severe cases of thalassaemia (beta-thalassaemia major) patients are dependent on blood transfusions for life, and have complications including bone deformation and growth retardation. In the UK sickle-cell disease is estimated to affect about 12,000 people mostly (but not exclusively) of African and Caribbean origin, while approximately 600 people have beta-thalassaemia major, mainly from the Mediterranean, the Middle East, and Asia.

My role is to offer psychological interventions and develop a service that is an integral part of a multidisciplinary approach to managing patients with sickle-cell disease and thalassaemia attending Central Middlesex Hospital, which has a clinic population of about 500 patients. My objective is to provide and direct a comprehensive psychological service that is hospital- and community-based, age-appropriate (paediatric and adult), and evidence-based. Achieving all this is quite a challenge and it requires clinical work, some research, teaching and training. The support I receive from an assistant psychologist, and sometimes from trainee clinical psychologists on placement, is much appreciated.

My working day is varied. I could be on a ward round in the morning, in therapy with an adult patient in the outpatient's clinic in the afternoon, and then working with a child and parent after school in the community. My typical week is structured to meet these daily demands. On Wednesdays, my day starts early with a multidisciplinary ward round where all members of the team (including haematologists, specialist nurses, and other specialists) are present to review in-patients and others of concern. Our opinions may differ on various issues, but we always have a consistent protocol-led approach to managing each patient. After the ward round I have outpatient consultations in a clinic suite, with children in the morning and adults in the afternoon. On a busy day I have just about enough time to grab a sandwich in between clinics.

Although I have my own consultation room (allowing confidentiality), occasionally I find it appropriate to have joint consultations with other clinicians, such as the paediatric neurologist. All sickle-cell and thalassaemia patients

attending Central Middlesex Hospital are assessed and treated using in-patient and outpatient protocols for good clinical practice. I have incorporated standard psychological measures into these protocols, allowing me to assess pain, mood, health-service utilisation, health beliefs, social support, and quality of life.

Other days of the week bring diversity, and I never know what to expect. I usually work with in-patients in a quiet room on the wards, and outpatients by appointment and walk-in basis in the clinic or in the Centre. My psychological interventions include pain and disease management based on cognitive-behavioural principles, and theories of gate control and cognitions in perceptions (i.e. self-efficacy and self-control). Specific applications include the use of pain and thought diaries, and activity schedules for self-monitoring. Central to this is a cognitive behaviour therapy programme for both children and adults, assisted by an innovative package funded by the Department of Health consisting of self-help manuals and a website. These manuals comprise patient education (including information about sickle-cell disease, pain, medical and complementary treatment), cognitive therapy, behaviour therapy, and relaxation. Both child and adult manuals can be obtained as a hard copy or downloaded from the web.

Quite importantly, I engage children and adolescents in psychoeducational groupwork. This is crucial because a lot of them do not know others with sickle-cell disease or thalassaemia. Groupwork is also based on cognitive-behavioural principles and offers an opportunity for sharing experiences and helping each other with ideas about coping with their condition. I usually organise group sessions during school holidays with the assistant psychologist and a specialist nurse. Children and adolescents may be shy at the beginning of the session, but will soon start talking, giggling, munching crisps, and working together. At the end of the session they would have learnt basic medical information and psychological coping strategies, enhanced with diagrams, videos and reading materials.

Additional interventions can be offered. These include motivational interviewing, incorporating the stages-of-change model (pre-contemplation, contemplation, action, maintenance, relapse) to assess readiness to change to help patients who are ambivalent about therapy or fluctuate in motivation to adhere to medical treatment, and problem-solving therapy for parents and carers to support children and adolescents. I also use theoretical models such as the locus of control, and the health-belief model. One of the main problems that face transfusion-dependent thalassaemia patients, and those on long-term transfusions for severe complications of sickle-cell disease (including stroke), is excessive accumulation of iron in the body. This iron overload is reduced by 'chelation therapy', involving overnight infusions of a drug called desferrioxamine and a low dose of vitamin C. This is a self-managed process; and sticking to it is a challenge, especially in adolescence when most patients begin to take responsibility for their medical care. What do you do with a teenager who says he feels good, so what is the big deal, why does he have to be chelating all the time? He just wants to 'hang-out' with the guys and be 'normal'. Well, my strategy is to employ a variety of interventions including providing information about long-term complications from iron overload, self-monitoring of chelation using diaries, and helping to find practical day-to-day solutions with his parents using problem-focused coping techniques. On balance, he can still go out with the boys if he has a nice trendy pouch to carry his chelation pump.

Research in the USA suggests cognitive impairment and deterioration of intellectual functioning in sickle-cell children, but evidence in the UK is limited. Nonetheless, I consult and liaise with schools and educational psychologists when such problems are indicated. I am currently developing a neuropsychology programme, which is aimed at patients living in the northwest London area, and pursuing research in neuropsychological problems to guide future interventions. After all, I still need more evidence.

'My work portrays the increasing involvement of psychologists in managing patients in a medical setting'

I have learnt over the years that in my real world of managing sickle-cell disease and thalassaemia there are some limitations with psychological approaches. It is unrealistic to assume that there is a clear-cut theoretical basis for every intervention, and it can be like trying to fit square pegs in round holes. Usually I modify my interventions to meet the idiosyncratic needs of patients. Moreover, psychology is a talking therapy, and at times I just have to accept that there is nothing I can do to help people who are very sick or in too much pain to engage.

This is my typical working day, varied and challenging in trying to help people of different ages, but what about yours? Is it similar or different? What approaches do you find helpful? Is there anything I could learn from you to improve my practice? Let's network and share some ideas, I will be happy to hear from you. After all, it is about helping to make the lives of others better!

■ *Dr Kofi Anie is at the Brent Sickle Cell and Thalassaemia Centre, Department of Haematology, Central Middlesex Hospital, London NW10 7NS. Tel: 020 8961 9005. E-mail: kofi@sickle-psychology.com.*

CALLING ALL PRACTITIONERS

Practitioners make up the bulk of the readership of *The Psychologist*, but we receive few submissions from them. As a membership publication we rely on your contributions, and our authors report that writing for us is a very positive and productive experience. Why not give it a go?

Formats include articles, debates, interviews, 'Personal space' pieces, and the new 'My working day' format. Your article should be written in an engaging and informative style for our wide-ranging audience. See *A Guide to Writing for The Psychologist*, available at *www.bps.org.uk/publications/thepsychologist.cfm* or from the Leicester office.

To discuss ideas or to submit your article, e-mail the Editor, Dr Jon Sutton, on jonsut@bps.org.uk.

WEBLINK

The Brent Sickle Cell and Thalassaemia Centre psychology website: *www.sickle-psychology.com*