

Better
Health
Briefing

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**The social
consequences
of sickle cell
and
thalassaemia:
improving the
quality of
support**

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Key messages

- 1 Greater understanding of sickle cell and thalassaemia is an important starting point in developing more appropriate and accessible care
- 2 Sickle cell and thalassaemia disorders are one of the most common genetic inherited conditions in the UK. The genetic nature of the two conditions raises the potential for screening interventions, which identify healthy carriers of the trait. Such interventions are increasingly common in the UK. Facilitating 'informed choice', however, is sometimes difficult to achieve in practice
- 3 Despite improvements in clinical management, poor service support remains a long-standing difficulty. The problem reflects a broader failure to engage with the social consequences of the conditions
- 4 Examples of good practice, in both health and social care, do exist. The potential of such interventions, however, is rarely realised and lessons remain poorly disseminated.

Introduction

Health and social care agencies have been slow to respond to the needs of those affected by sickle cell and thalassaemia (Anionwu and Atkin, 2001). Despite recent improvements in clinical management, inadequate, ill coordinated and poorly resourced services remain long-standing problems (UK Thalassaemia Society, 2005; Lucas *et al.*, 2008; Sickle Cell Society, 2008). The genetic nature of these conditions also raises the possibility of screening interventions, which identify healthy carriers of the trait. Such interventions are increasingly common in the UK, but generate potential tensions, which are rarely addressed, especially by local policy and practice.

This briefing paper engages with the experience of those with the conditions, alongside a reflection on current screening policies. Our introduction on the origins and consequences of the conditions is not intended to support a medically orientated account, whose narrow focus can sometimes be a barrier to developing support. Nonetheless, since a lack of basic knowledge on the part of health and social care practitioners and 'at-risk' communities has been identified as a particular shortfall, a good understanding of the conditions is an important starting point.

1 Improving understanding

Sickle cell and thalassaemia are recessively inherited disorders of haemoglobin, the oxygen-carrying substance found inside red blood cells (Okpala, 2004). Both parents must be carriers of a haemoglobin trait before the particular condition can be passed on to their children. When both partners carry a trait, there is a one in four risk in every pregnancy that their child could be born with either a sickle cell or a thalassaemia disorder. A simple blood test can detect whether someone is a healthy carrier.

There are estimated to be at least 240 000 sickle cell trait carriers and 214 000 thalassaemia trait carriers in the UK (National Screening Committee for Sickle Cell and Thalassaemia, 2006). An individual who carries a trait cannot develop the illness. In fact, if living in the tropics, traits seem to offer some protection against malaria, especially in early childhood. The frequency of haemoglobin traits for the more common ethnic groups living in the UK can be found in Table 1. The distribution of haemoglobin traits is, however, wider than this (see Modell and Darlison, 2008).

Table 1 Frequency of haemoglobin traits for specific ethnic groups (UK)

Haemoglobin type	Ethnic group	Carrier frequency
Sickle cell trait	African Caribbean	1 in 10
	West/Central African	Up to 1 in 4
	Cypriot	1 in 100
C trait	African Caribbean	1 in 3
	Ghanaian	Up to 1 in 6
D trait	South Asian	1 in 100
Alpha thalassaemia	Chinese	1 in 15 to 30
Beta thalassaemia	Cypriot	1 in 7
	South Asian	1 in 10 to 30
	African Caribbean	1 in 50
	White British	1 in 1000

(Source: Anionwu and Atkin, 2001)

Sickle cell disorders

There are at least 14 500 people with sickle cell disorders living in the UK (National Screening Committee for Sickle Cell and Thalassaemia, 2006). Sickle cell disorder is an umbrella term and includes sickle cell anaemia (usually the more severe type and sometimes referred to as SS disease), haemoglobin SC disease, SE disease (both usually milder) and sickle beta thalassaemia (of which there is both a severe and a mild form).

Under certain circumstances, such as dehydration, infection, sudden changes in temperature, physical trauma and emotional stress, the red cells change their shape and resemble a half-moon or farmer's sickle. 'Sickled' cells can cause blockages in smaller blood vessels. Affected individuals might experience mild to excruciating pains and damage to various parts of the body, including the hips, eyes and lungs. The majority of those affected survive into adulthood, but occasional deaths occur in childhood due to complications associated with overwhelming infections (such as pneumonia, meningitis and salmonella). Children are also vulnerable to strokes. Current management includes the prevention of infections by the use of daily penicillin and vaccines, in addition to daily dosages of folic acid. Exchange blood transfusions are occasionally used for certain complications, especially following a stroke or for those identified at risk of a stroke. In severe cases, bone marrow transplantation is considered, although clinicians and families have to balance the uncertainty associated with the condition's progression with the risk associated with transplantation.

Alpha thalassaemia

When both parents are carriers of the severe type of alpha thalassaemia, their unborn baby could inherit alpha thalassaemia hydrops fetalis. This leads to a total absence of fetal haemoglobin and causes stillbirth. There is also some danger to the mother, as she is likely to develop pre-eclampsia (leading to life-threatening high blood pressure and retention of fluid). Most carriers of the severe alpha form of thalassaemia usually originate from Hong Kong, China, Singapore and Vietnam, as well as Cyprus, Greece and the Middle East. A mild form of alpha thalassaemia exists and is not usually clinically significant. It is usually carried by people originating from Africa, India and Pakistan (see Okpala, 2004).

Beta thalassaemia

In the UK, between 700 and 1000 people have beta thalassaemia major (also known as thalassaemia major), about 65 per cent of whom are under eighteen years old. Those at risk of inheriting beta thalassaemia are people of Mediterranean and Southern European, Asian, Middle Eastern and Far Eastern origin. A person born with beta thalassaemia major is unable to make sufficient red blood cells and will develop a fatal anaemia in early childhood if not treated with monthly blood transfusions (see Okpala, 2004). This treatment, however, causes an excess of iron to be stored in the body, which has to be removed by a process called chelation. In the past, the child had to be taught from an early age how to use an infusion pump containing a drug (Desferrioxamine) that helps the body get rid of this excess iron. The recent development of an oral chelator, usually taken as a tablet (Deferiprone) or chalky drink (Exade), on its own or in combination with an infusion pump, has simplified treatment, although it might not be suitable for all patients, as significant side-effects have been reported for some. Complications associated with beta

thalassaemia and its treatments include cardiac problems, diabetes, delay in entering puberty, osteoporosis, hypothyroidism and other endocrine problems. Other consequences can sometimes include infections acquired through blood transfusions, such as hepatitis C and HIV. Iron overload remains the most common cause of premature death, although in the UK, 'well-managed' thalassaemia patients are now living into their sixth decade. Many successful bone marrow transplants have been undertaken for thalassaemia major, but finding an appropriate donor remains a problem. Bone marrow transplantation, however, carries considerable risks and even when successful, fertility impairment is often an outcome.

2 Screening policy

The government has recently implemented a national screening programme in England for women whose pregnancy is 'at risk' of a sickle cell or thalassaemia disorder. Alongside this ante-natal screening programme, the NHS also aspires to identify all newborns who have a sickle cell disorder, irrespective of ethnic origin ([National Screening Committee for Sickle Cell and Thalassaemia, 2006](#)). Prior to this, screening was extremely ad hoc (see [Atkin *et al.*, 1998](#)).

Women and their partners, identified as trait carriers, are offered pre-natal diagnosis, ideally during the first three months of the pregnancy, with the option of either continuing or terminating the pregnancy. Late screening, however, remains a problem; 74 per cent of women consult for pregnancy before ten weeks' gestation, but fewer than 5 per cent are offered screening before the recommended target time of ten weeks ([Dormandy *et al.*, 2008](#)). Such delays continue to undermine parents' ability to exercise informed choice.

Screening can also present parents with difficult and complex choices ([Rowe *et al.*, 2004](#)) and this is not always understood by some health care professionals. Parents, for example, struggle to make a decision, particularly when many have little prior understanding of the condition. Understanding of thalassaemia among South Asian communities is a particular issue ([Shaw, 2009](#)). Community engagement, which attempts to raise people's understanding of the conditions and make it part of their broader health literacy, can be an important step forward in facilitating informed choice ([Kelly, 2007](#)).

Such understanding might also be important in challenging some of the more normative assumptions informing the decision-making process. Mothers, for example, often accept screening (and the possibility of termination) with little discussion because their sense of 'good motherhood' suggests that they should do all they can to produce a 'healthy' baby ([Dormandy *et al.*, 2010](#) forthcoming). This is also why they express a high degree of trust in health care professionals, rarely questioning the offer of a screening test. More generally, prospective parents say that decisions about termination are informed not only by their perceived severity of the condition, but also by how they think the broader society treats people with disabilities and long-standing conditions ([Atkin *et al.*, 2008](#)). Consequently, informed choice can be a lot more complicated than is sometimes assumed by health care policy, and understanding of how people make the decisions they do needs to be improved ([Williams, 2006](#)).

The newborn screening programme will go some way to preventing delays in diagnosis, which were a feature of the past literature. These delays prevented effective early treatment, which would have reduced complications and deaths among children, and caused parents considerable distress ([Anionwu and Atkin, 2001](#)). Since such screening also identifies trait carriers, ethical dilemmas arise over the timing of disclosure. Stigma might also be an issue.

The availability of more accurate screening data has begun to challenge some of the assumptions associating sickle cell and thalassaemia disorders entirely with minority ethnic populations. National screening programmes have identified far more 'white' carriers than expected and the increasing proportion of populations who claim 'mixed heritage', together with the arrival of refugees and asylum seekers, further complicates the situation ([Dyson, 2005](#)).

The social consequences of sickle cell and thalassaemia disorders

Individuals with sickle cell and thalassaemia disorders, and their families, encounter various psychological, social and material challenges. There is considerable variability in the way individuals respond and adapt to these challenges (Burlew and Telfair, 2000), with no apparent clear association between severity and psychosocial adjustment. Indeed, some seem to experience no greater psychosocial impairment than their healthy peers (Anionwu and Atkin, 2001).

Sickle cell disorders, however, are highly variable, creating considerable uncertainty (Anie *et al.*, 2002). A definitive prognosis is not possible, much to the frustration of affected individuals and their families (Anionwu and Atkin, 2001). An individual might go many years and not experience a painful crisis, but then have three or four within a six-month period. Similarly, damage to organs remains probable rather than inevitable.

Management of the painful crisis, one of the main characteristics of sickle cell disorders, can range from home treatment with mild painkillers to the hospital administration of powerful drugs. Individuals not only have to deal with the practical, psychological and emotional consequences of pain, which is considerable and at times poorly managed in NHS settings, but also express anxieties about what their families are going through (Lucas *et al.*, 2008). Family members, for their part, describe the difficulties of seeing a loved one in pain and knowing there is little they can do to help them (Anionwu and Atkin, 2001). Institutional racism might also explain some of the problems faced by individuals and their families (Elander *et al.*, 2004). Stereotypes of minority ethnic patients having a lower pain threshold means they do not always receive the care they need (Anionwu and Atkin, 2001). The lack of treatment can also be influenced by another myth, with health care professionals worrying about 'black' patients becoming dependent on drugs, despite there being no evidence that this is a widespread problem (McCaffery and Pasero, 2001).

For those with beta thalassaemia, the use of chelation therapy often becomes the defining feature of their experience. Difficulties in concordance are commonplace, although practitioners often misunderstand these.

Resources 1

All Party Parliamentary Group on Sickle Cell and Thalassaemia

This group, chaired by Diane Abbott, MP, holds regular meetings and invites representations from any individual or organisation. Their recent publication, *Sickle Cell Disease and Thalassaemia: A health check*, for example, establishes a manifesto for improved provision. See: www.sicklecellsociety.org/pdf/APPG%20booklet.pdf

OSCAR

There are several regional OSCARs in the UK, including Birmingham (www.oscarbirmingham.org.uk), Sandwell and Dudley (www.oscarsandwell.org.uk) and Bristol (www.oscarbristol.co.uk). Their aim is to raise awareness of sickle cell, provide support and advice and lobby for improvements in service.

Sickle Cell Society

www.sicklecellsociety.org

The Sickle Cell Society's mission statement states that the Society 'believes that every sickle cell sufferer has the right to quality care. This can only be achieved if funding is made available to educate health carers and other professionals about the condition. The Society aims to provide this'.

UK Thalassaemia Society

www.ukts.org

The UK Thalassaemia Society represents the interests of those with thalassaemia and their families. The organisation provides advice and support and lobbies for improved support and care. It also produces a regular newsletter.

Other support groups include: **Sickle Cell Young Stroke Survivors** (www.scyss.org); **North of England Bone Marrow and Thalassaemia Association** (www.cmft.nhs.uk/directorates/nebata/default.asp); **Broken Silence** (www.brokensilence.org); and **ASYABI** (www.asyabi.co.uk).

For those with thalassaemia, treatment assumes more of a symbolic and emotional significance, becoming a constant reminder of the difficulties they face, as they attempt to assert their normalcy ([Atkin and Ahmad, 2000](#)).

Comprehensive care, involving a broad range of health and social care agencies and provided by a multidisciplinary team, has many advantages, including: reduced mortality and morbidity; reductions in hospital admissions and length of stay; and greater person and family satisfaction ([UK Thalassaemia Society, 2005](#); [Sickle Cell Society, 2008](#)). Medical care, however, remains patchy and the role of social services and of housing, education and employment services is poorly developed ([All Party Parliamentary Group, 2009](#)). Consequently, the potential of multi-agency care is rarely realised. Social care and associated agencies should be specifically encouraged to provide advice on benefits, alongside assessment of social and housing needs ([UK Thalassaemia Society, 2005](#); [Sickle Cell Society 2008](#)). Social isolation is a real possibility for those with sickle cell and thalassaemia disorders.

Young people and their families describe education services as particularly unresponsive ([Dyson *et al.*, 2008](#)). There is little evidence that the guidance associated with the Education Act 1996, asking schools to make suitable arrangements for children who miss school because of illness, informs the care of those with sickle cell and thalassaemia disorders. In addition, few young people receive what they regard as useful career advice at school. Greater employment support and training opportunities would also help ([Sickle Cell Society, 2008](#)). People with sickle cell and thalassaemia disorders specifically find it difficult to gain fulfilling and financially rewarding employment, either because of a lack of support or as a consequence of employers' ignorance, inflexibility and inability to accommodate difference ([All Party Parliamentary Group, 2009](#)). Ignorance can equally characterise an individual's contact with benefit agencies ([Anionwu and Atkin, 2001](#)).

4 Improving care

Coping with a sickle cell or thalassaemia disorder is not associated wholly with intrapersonal factors. Family support, the response of services and access to material resources are equally important ([Rouse, 2009](#)). Similarly, threats to normalcy do not always reside in the condition: life transitions, changes in social relationships, poor service delivery and racist or disabling responses from others equally threaten adaptation ([Anionwu and Atkin, 2001](#)).

Examples of good practice in health and social care do exist and there are many instances of innovative, sensitive and empowering provision. Sickle cell and thalassaemia specialist counsellors exemplify this, and their role in

Resources 2

Several important guidelines for clinical care have been produced by those working in the field. ***Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK*** was published by the UK Thalassaemia Society and is available on their website. ***Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK*** and ***Standards for the Clinical Care of Children with Sickle Cell Disease in the UK*** have been published by the Sickle Cell Society.

A report, ***Informal Review of Clinical Networks in Haemoglobin Disorders in England***, authored by paediatrician Phillip Darbyshire (2010), provides further evidence-based guidance on the care of those with sickle cell and thalassaemia disorders (copies are available from kathryn.flynn@dh.gsi.gov.uk).

Two projects, funded by the Health Technology Assessment programme, add further to our understanding. Professor Joe Kai and his team have looked at communication of carrier status information following newborn screening (see: www.hta.ac.uk/project/1510.asp). Professor Theresa Marteau and her team have looked at where best to provide ante-natal screening (see: www.hta.ac.uk/project/1401.asp).

Professor Simon Dyson and his team will provide the first comprehensive study on education and sickle cell (see: www.dmu.ac.uk/research/hls/thalas_research/index.jsp).

providing culturally sensitive care is well documented (Dyson, 2005). Coverage, however, is not widespread and balancing a screening role with a more caring role can sometimes create difficulties. Patients living in localities, where few other people have the conditions, can be especially disadvantaged. Other important developments include establishing comprehensive centres and day care (Wright, 2004) and the increasing use of self-management as a form of empowerment (Anie, 2004). Such activities, however, remain uncoordinated and successes in one locality do not seem to be readily translated into successes in another (Lucas *et al.*, 2008). This contrasts with the development of care for cystic fibrosis and haemophilia. A more considered and coordinated approach to service delivery would, therefore, be welcome.

Recent policy emphasis and resource allocation has tended to focus more on screening, at the expense of the care agenda (Anionwu, 2008), while both are, of course, equally important. Partnerships between enlightened service practitioners and voluntary organisations are beginning to challenge this inequity, and serve as a reminder more generally of the importance of such relationships in ensuring that sickle cell and thalassaemia remain on the national and local policy and practice agenda (Anionwu and Atkin, 2001).

The recent launch of documents establishing clinical standards in sickle cell and thalassaemia disorders has been a welcome development (UK Thalassaemia Society, 2005; Sickle Cell Society, 2008), as is the establishment of an All Party Parliamentary Group, which has led to a series of parliamentary questions. There is currently, however, no intention to evaluate the implementation and impact of recently developed clinical standards. This reflects another long-standing problem, that evidence rarely informs practice, except in localities where there are large numbers of individuals with sickle cell or thalassaemia disorders. A report, authored by Phillip Darbyshire (2010) and commissioned by the Department of Health, is likely to make an important contribution to this debate. The interest of the National Institute for Health and Clinical Excellence (NICE) in pain management for people with sickle cell disorders is also helpful (see NICE, 2009).

Voluntary and community organisations continue to highlight the marginalisation of these conditions and remain an important voice in developing service provision and advocating on behalf of those with the conditions, and their families. History suggests that their involvement is fundamental in developing good practice, but resources continue to be a problem. In 2008, the Sickle Cell Society raised £300,000, whereas the Cystic Fibrosis Trust raised £11.5 million (Hobson, 2008).

Conclusion

Little more than twenty years ago, sickle cell and thalassaemia disorders could be dismissed as conditions of little interest to health and social care agencies. Much has been achieved since then, although ensuring the ongoing development of services and the dissemination of good practice remains a struggle. Service coordination, evidence-based practice, inter-agency collaboration and strategic leadership represent key challenges, as does the need to provide equitable care, wherever a person might live. Managing the tension between screening at-risk populations while providing appropriate and accessible support services for those with the conditions, is likely to be another important feature of future policy and practice developments.

Resources 3

NHS Sickle Cell and Thalassaemia Screening programme

<http://sct.screening.nhs.uk>

This website contains information about sickle cell and thalassaemia and other haemoglobinopathies. The website is an excellent source of advice both for the public and for service practitioners. For example, one of the many outcomes of the programme is *The Family Legacy*, a short film, which aims to increase public awareness of the consequences of screening. See: <http://sct.screening.nhs.uk/familylegacy>

PEGASUS

www.pegasus.nhs.uk

PEGASUS is an education site, providing information on genetics aimed at NHS professionals working with those at risk of sickle cell and thalassaemia disorders.

Accessible Publishing of Genetic Information (APOGI)

www.chime.ucl.ac.uk/APoGI/menu.htm

This is also an excellent source of information on the complexities of genetic transmission in sickle cell and thalassaemia.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

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