The blood disorders that nursing students are failing to learn about

Lack of education and training on sickle cell and thalassaemia is leaving patients at serious risk, experts warn

One in five universities is failing to educate nursing students on two potentially life-threatening blood conditions, a Nursing Standard investigation has found.

Of 70 UK universities that offer undergraduate nursing degree courses who responded to our Freedom of Information request, 15 said they don’t devote any teaching time to sickle cell disease. The serious inherited blood disorder can cause episodes of severe pain known as ‘crises’, which can require emergency hospital treatment and can even cause death without the right care.

Not in the curriculum
Nor do those 15 universities teach nursing students of any specialty about thalassaemia, a group of inherited blood disorders that affects haemoglobin production.

This is despite calls from leading nurses and patient groups for all preregistration nursing students to be taught about the two conditions, which together affect thousands of people in the UK.

At present, every university can set its own nursing curriculum and there is no requirement to cover the conditions.

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But this means patients could be missing out on vital care because health professionals are not adequately trained in dealing with symptoms, says Giselle Padmore-Payne, a Roald Dahl lead transition clinical nurse specialist at King’s College Hospital NHS Foundation Trust in London.

What students need to know
She says the complex nature of the conditions and their prevalence mean they warrant a standalone module in the curriculum so that all nurses know how to provide effective care. ‘Sickle cell and thalassaemia blood disorders have been underfunded and underestimated,’ she says. ‘Patients have died because of the lack of awareness when it comes to sickle cell and how dangerous it can actually be.

‘People are recognising that there needs to be more education about sickle cell and thalassaemia because there is quite a big [patient] population, especially in cities like London.’

Nursing Standard asked all 77 UK universities that run undergraduate nursing courses whether they currently teach students about sickle cell and thalassaemia, or plan to in the future. Of the 70 that responded, 54 said that they teach students about them as part of modules on other long-term conditions or blood disorders. One institution said it teaches students about sickle cell disease only.

Teaching time varies from one hour to nine hours over a three or four-year course.

Ms Padmore-Payne says enough time needs to be devoted to the symptoms and treatments of the conditions, so people can receive the best possible care.

‘When people hear the words sickle cell, they tend to think that it’s just a bit of pain,’ she says. ‘[Healthcare professionals] give patients some pain relief and think they will be fine.’

She says lack of awareness of potential complications is especially concerning. In sickle cell, this includes an increased risk of infection as well as stroke and lung problems.

What students are learning
Our findings follow a call for all nursing students to graduate from university with knowledge of the conditions.

The All Party Parliamentary Group on Sickle Cell and Thalassaemia (SCTAPPG) campaigns to keep sickle cell and thalassaemia at the top of the political agenda, and to ensure that policy-making remains patient-centred.

The group’s 2018 report I’m in Crisis said that of 197 students surveyed from nine nursing and midwifery schools and faculties, 71.1% said they had not had any formal teaching sessions about sickle cell and 80.7% had not had any formal teaching about thalassaemia.

One university told Nursing Standard that it taught sickle cell and thalassaemia to children’s nursing students, but not to adult nursing students.

Lola Oni, specialist nurse consultant, lecturer and service director at Brent Sickle Cell and Thalassaemia Centre in London, described such a decision as ‘ludicrous’. Dr Oni, who is also chair of Sickle Cell and Thalassaemia Association of Nurses, Midwives and Allied Professionals, says: ‘Aren’t those children going to grow up? These are lifelong conditions, not children’s conditions.’

Dame Elizabeth Anionwu, patron of the Sickle Cell Society, set up the first nurse-led sickle cell intervention and screening service in England. Now every baby in the country is screened for the disease.

Sickle cell disease is particularly common in people of African or Caribbean heritage, while thalassaemia mainly affects people from a Mediterranean, south Asian, southeast Asian and Middle Eastern background.

Patients of all backgrounds
Professor Anionwu says there is a ‘dangerous’ misconception that the issue is only relevant for health professionals training or working in larger cities, such as London. ‘What happens when that qualified nurse then moves and works in an area where this condition is relevant?’ she says.

‘Certainly, you do hear patients saying, “the nurse has been honest and said I don’t know anything about it, please tell me a bit about your illness”. Imagine the anxiety that can cause the patient.’

Professor Anionwu says all front-line staff should have access to a helpline for advice on the conditions from a trained professional. ‘Patients can go on holiday; they could be children in care. Patients living with...’

‘Patients have died because of the lack of awareness of sickle cell and how dangerous it can be’
Giselle Padmore-Payne, Roald Dahl lead transition clinical nurse specialist, King’s College Hospital NHS Foundation Trust, London.
People living with sickle cell disease produce unusual shaped red blood cells that can block blood vessels. The blockage can cause severe pain, often referred to as a crisis. Strong painkillers such as morphine are given to manage the pain.

She adds that more work needs to be done to dispel the myth that thalassaemia only affects people of certain backgrounds. ‘I met a woman who is Welsh [and white] and who was tested in pregnancy and found she was a beta thalassaemia carrier. Her midwife was surprised: she said she only thought it affected the Greek population. Many associate the word with certain ethnicities.’

Training for front-line staff too

RCN head of learning and development Nichola Ashby says: ‘Nursing degree programmes are a useful way to introduce students to a range of clinical topics that will benefit their practice postregistration. ‘Raising awareness of conditions such as sickle cell anaemia and thalassaemia is an important first step to improving the long-term care people with these conditions require.’

In September, it was announced that every nurse providing NHS services in England will have access to a £1,000 continuing professional development (CPD) fund spread over three years. ‘The government announcement on personal training budgets for nurses is a great first step to addressing this, but nurses must be given sufficient time by managers to actually take up courses and attend conferences,’ Ms Ashby adds.

High quality, culturally safe care

Devoting teaching time to the two conditions might present a challenge, but it is an important addition, says Stacy Johnson, associate professor at the University of Nottingham’s school of health sciences. ‘As a nurse lecturer, I understand the challenge of including specific conditions in an already packed curriculum, but attention is needed as the current education provision is variable and is contributing to inequalities in access to appropriate care,’ says Ms Johnson, who is a member of SCTAPPG and the chief nursing officer’s Black and Minority Ethnic Advisory Group.

‘Service users’ accounts, the casework of sickle cell and thalassaemia charities and our work on behalf of the SCTAPPG suggests that more needs to be done to prepare nurses to deliver high quality, culturally safe care to this group of patients.’

Sickle Cell Society sicklecellsociety.org

UK Thalassaemia Society ukts.org

All Party Parliamentary Group on Sickle Cell and Thalassaemia sicklecellsociety.org/ctappg

Sickle cell and thalassaemia: what you need to know

Sickle cell disease

- Sickle cell disease is the name for a group of blood disorders, the most common and severe is sickle cell anaemia
- People living with sickle cell disease produce unusual shaped red blood cells that can block blood vessels. The blockage can cause severe pain, often referred to as a crisis. Strong painkillers such as morphine are given to manage the pain
- Can affect people of any race but is most common in people of African or Caribbean heritage
- Complications of sickle cell disease include stroke, acute chest syndrome, blindness, bone damage and priapism (a persistent, painful erection)

Thalassaemia

- People with thalassaemia produce little or no haemoglobin, which can make them anaemic
- Can affect people from all backgrounds, but more common in those from a Mediterranean, south Asian, southeast Asian and Middle Eastern background
- The two main types are alpha thalassaemia (when the body has difficulty producing alpha globin) and beta thalassaemia (difficulty producing beta globin)
- Symptoms include severe tiredness; shortness of breath; weakness; pounding, fluttering or irregular heartbeat
- Patients may require regular blood transfusions. This can produce too much iron in the body, triggering problems with the heart, liver and hormone levels

Source: NHS information on sickle cell disease nhs.uk/conditions/sickle-cell-disease

Source: NHS thalassaemia information nhs.uk/conditions/thalassaemia