Recommendations aim to support sickle cell disease and thalassaemia specialist nurses

Protecting specialist roles in haemoglobin disorders

In this article...

- Role of specialist nurses for sickle cell and thalassaemia
- Recommendations on protecting and strengthening the role

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Abstract

The specialist nurse role for sickle cell disease and thalassaemia must be protected and strengthened, says a report launched at the 2012 Royal College of Nursing Congress (Anionwu and Leary, 2012). The report investigates the roles and how their expertise benefits patients. It highlights nurses’ vital role in managing these complex multi-system conditions, and draws on evidence from a specially commissioned project.

Sickle cell disease and thalassaemia – collectively known as haemoglobinopathies – are genetically inherited disorders of haemoglobin. The effects can include pain, severe anaemia, infection susceptibility and major organ damage. Specialist nurses work in the community or acute trusts, providing a range of services to adults and children with the disorders, including genetic counselling, disease monitoring, controlling symptoms, psychosocial interventions, family support, providing information, and referring to appropriate agencies.

The project
In 2011 the All Party Parliamentary Group on Sickle Cell and Thalassaemia convened to discuss the implications of the economic climate for specialist nursing posts. A project was commissioned to ascertain the contribution of sickle cell and thalassaemia nurses in community and acute settings for adult and paediatric care. Data from complex activity analysis, in-depth interviews and a literature review were analysed.

The report emphasises the value specialist nurses bring to the NHS Quality, Innovation, Productivity and Prevention (QIPP) initiative; it describes their role as vital. Patients and families regard these nurses as invaluable as they are often the continuum in the patient journey. Much of their work involves managing caseloads that include antenatal and paediatric care, as well as teenage, adult and older patients. They are familiar with the unpredictable nature of sickle cell disease and cultural issues around haemoglobinopathies. Given a choice, many patients say they would rather receive care from their specialist nurse than a GP, for example, due to their knowledge of the conditions’ nuances.

Recommendations
- Posts should be commissioned where needed. Lack of expert care is costly in the long term, causes distress and leads to poor clinical outcomes and experiences. Patient/specialist nurse ratios should be on a par with those of other long-term conditions.
- A national census of specialist nurse posts for sickle cell and thalassaemia should be undertaken to gain a better understanding of the current workforce and inform workforce planning.
- Existing specialist nurse jobs should be protected. Expert nursing care keeps people out of hospital (reducing costs) and helps them live healthier, productive lives (improving outcomes).
- Time to care should be released, maximising specialist nurse time. Clerical work can be delegated.
- Specialist nurses should focus on enabling self-management and reducing complications, helping patients and families to understand their conditions and look after themselves, preventing unscheduled admission where possible.
- Regular work to capture patients’ and families’ views and experiences should be carried out to ensure nursing care meets patients’ needs.
- Trusts should engage with specialist nurses to recognise and encourage a greater contribution to the NHS QIPP agenda. They can increase productivity and use nurses’ insight to perform robust service reviews.
- Clear job descriptions should be established to eliminate the multiplicity of job titles and define the specialists’ role.
- Access to appropriate accredited education and resources for specialist nurses should be ensured, with support offered through bursaries, commissioned places and study time.
- Nursing services should be organised based on clinical need and enable seamless, integrated specialist nursing care across acute and community settings.
- Equitable access to expert care should be offered across all geographical areas.
- The lack of research in sickle cell and thalassaemia should be addressed. Recommendations will be more robust and benefit from further research.

Other work
The project builds on the launch of the RCN (2011) accredited nursing competencies, which was a key step towards incorporating guidance about haemoglobinopathies in mainstream nurse training. The East Midlands Specialised Commissioning Group recently launched the National Haemoglobinopathies Project, a framework for sickle cell and thalassaemia, providing a set of guidance documents for commissioners (see tinyurl.com/NHP-more-info). NT

References
Royal College of Nursing (2011) Caring for People with Sickle Cell Disease and Thalassaemia Syndromes. A Framework for Nursing Staff. tinyurl.com/RCN-sickle-cell

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