The New Adult Sickle Cell Standards - Implications for Community Care
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COMMUNITY HAEMOGLOBINOPATHY SERVICE PROVISION

OBJECTIVES

• Promote community awareness and the education of health, allied professionals & lay groups

• Promote access to appropriate screening and counselling services and enable those at risk to make informed genetic choices

• With the acute & community multidisciplinary team provide care for individuals with disease states and support their families and local community
ACTIVITIES OF COMMUNITY SPECIALIST CENTRES

- Screening /testing & counselling service
  - Antenatal
  - Neonatal
  - General population
  - Opportunistic e.g. pre surgery
- In & Outpatient management & support
- Multi sectoral collaboration
  - Data management/ Research/ Audit
  - Education (local/ national/ international)
- Development of policies/ guidelines/ protocols and educational resources
Standard 1
All adults with SCD should have access to community nursing support
Adult Standards 2018: 55
“The community specialist nurse has an important role in encouraging self-management and more general health promotion for people of all ages living with SCD”

Adult Standards 2018: 55
“... objective (is) to incorporate specialist nursing care into the treatment plan of a patient, with the aim of providing a positive impact to patient care including the recovery time of people that endure (outlasts) a sickle cell crisis”

Anionwu & Leary 2012: 4
“Community healthcare professionals should provide information and other support to enable patients to become experts in their own care so they can fully participate in their own care planning”.

East Midlands Commissioning Group 2011: 60
Standard 2
The number and case mix of specialist nurses in the community should be regularly evaluated to ensure that services have adequate staffing levels in line with the duties they are undertaking.

Adult Standards 2018: 55
“The redesign and transformation of health and social care services must recognise nurses’ leading role in caring for people with long-term conditions. Care pathways must be commissioned for service users that maximise the nursing contribution.”

Anionwu & Leary 2012:10
Community haemoglobinopathy staff should benefit from close working arrangements with other healthcare professionals managing other long-term conditions; they should also benefit from the same service development opportunities present in other chronic disease groups.

East Midlands Commissioning Group 2011: 58
Standard 3
Specialist community nurses should receive appropriate training, supported by certification and competencies to be evaluated as part of their annual professional practice review.

Adult Standards 2018: 55
“Commissioners should work with NHS Trusts and Health Boards to ensure the delivery of clinical networks of care for children and adults with sickle cell disease (SCD) (in all care settings)”.

NHS Blood & Transplant (2014: 14) *National comparative audit of blood transfusion*
Standard 4
Clear arrangements for shared care between the community team and local hospital should be in place. This should include multidisciplinary team meetings.”

Adult Standards 2018: 55
“every effort must be made to co-ordinate care between different specialties to avoid omission or unnecessary duplication. This includes developing good working relationships with secondary and tertiary care providers, along with the sharing of information.”

Adult Standard 2018: 52
NHS England Haemoglobinopathy Clinical Reference Group proposals

- National MDT
- Regional Network of care
- Local care providers
Planning for the future
Application of the new Adult standards to practice

Mrs Nkechi Anyanwu
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Patient engagement

• How can we empower our clients to use this document?
• Going to local support groups, encouraging acute sector to include the link for the document in discharge letters.
• ‘Patient engagement can deliver more appropriate care and improved outcomes’
  
  (King’s Fund, 2012)
“Staff at sickle cell and thalassaemia community centres should be prepared to offer guidance to colleagues in local community services that the patient has contact with.”

Adult Standards 2018: 56
Other Community Care Providers

• Educate and raise awareness of the standards with other generic Community Nurses (Practice Nurses, District nurses & Family Practice nurses etc).

• To be able to support Sickle cell patients they should be aware of the document and implement it as part of their chronic disease management.
Knowledge vs. Empowerment

• Collaborative work with primary care to ensure sickle cell patients adhere to prescribed care as set out in the adult standards.
• Good publicity of the standards in primary care settings e.g. posters, leaflets and social media
• Encourage GPs to use the Standards as a working tool in – monitoring, prevention and management of SCD in the community.
“Community healthcare professionals are able to act as a key point of liaison (named nurse) between the range of healthcare providers and other agencies that may be supporting the patient / family”.

East Midlands Commissioning Group 2011: 61
Chronic Disease Management Model:

**Level 1** – Self managed Chronic Care Management patients (70-80%)

**Level 2** – High risk patient, need interventions, with some support can become self managing (20%)

**Level 3** – High risk with possible co morbidities requiring MDT acute and community care, increased risk of complications & hospitalisation (10%)

DoH 2004 in Anionwu & Leary 2012 & DoH 2005
Develop national guidelines using the Chronic Disease Care Model applied to haemoglobinopathies measurable against the new adult standards (working groups in STANMAP)
“Self management support services in the patient’s home” pg. 56

- Adherence to prescribed treatment
- Chronic pain management
- Health promotion and education
- Preventive interventions and guidance
• Key (lead) community specialist Carer – coordination of community management
• Nurse led community clinics
• Discharge planning with acute MDT
• Community clinical care – assessment, implementation and review of care
• Develop community guidelines/ protocols/ educational resources/ PEER Reviews
• Data management / research/ audits/ user views
“Supporting early discharge from hospital and offer continuing good quality care in a home setting”.

Adult Standards 2018: 56
“The primary care team should let the hospital team know if the patient is not collecting prescriptions (e.g. for antibiotics) regularly.”

Adult Standards 2018: 53
“GPs should keep records of a person’s carrier status and offer timely reproductive advice, when appropriate. They should also offer advice on the implications of being a carrier for the individual and family members.”

Adult Standards 2018:54
“An element of effective community care will be signposting patients to other statutory and voluntary bodies that may be able to assist with wider determinants of health”

East Midlands Commissioning Group 2011: 58
Advocacy, Welfare Advice and Family Support

• By implementing the document we uphold welfare support and advocacy for Sickle Cell Patients, their families, guardians and carers by providing a holistic service which works with the entire family.
Possible Challenges

• Lack of enforceable policies
• Poor management/ lack of vision
• Workforce shortages/ retirements
• Financial constraints
References:

• Anionwu E, Leary A (2012) *Understanding the contribution of sickle cell & thalassaemia Specialist Nurses* Sickle Cell Society UK

• East Midlands Specialist Commissioning Group (2011) *The National Haemoglobinopathies Project a guide to effectively commissioning high quality sickle cell and thalassaemia services* DoH

  Accessed May 2018
References:

- The King’s Fund (2012) *Leadership and engagement for improvement in the NHS. Together we can*. Report from the King’s Fund leadership review
Thank You