ACUTE AND CHRONIC PAIN MANAGEMENT IN SICKLE CELL DISEASE: OUTCOMES OF AN ENGLISH NATIONAL AUDIT.

Background: Acute pain is the most common complication of sickle cell disease (SCD). Patients suffering severe pain often seek treatment in an acute hospital setting. Feedback from service users indicates a lack of satisfaction with quality of care. NHS England specialised commissioning recommended forming a National Sickle Pain Group (NSPG) consisting of multi-professional stakeholders and patient representatives, to understand the range of practices and challenges in providing high-quality hospital care.

Aims: The objective was to develop national guidelines for acute and chronic pain management which will improve quality of care, patient experience and outcomes. The aim was to understand the variety of acute and chronic pain management policies and protocols used across England, identify aspects of care where there was unacceptable variation and examples of good care.

Methods: A questionnaire was developed through discussion meetings with members of the NSPG. This was sent to haemoglobinopathy coordinating centre (HCC) leads, to be distributed to all specialist haemoglobinopathy teams (SHTs) and local haemoglobinopathy centres (LHTs) in their network, inclusive of adult and paediatric services.

Results: In total, 56 services (26 paediatric and 30 adult departments), in 39 centres completed the questionnaire (75% response rate). Of these, 51% were LHTs, 15% SHTs and 33% HCCs. The size of services varied between 0 and 808 patients for adult services and 0 and 439 patients for paediatric services. Hospital admissions with vaso-occlusive episode in the year April 2020 to March 2021 for adult services varied between 0 and 754. Admission rates in paediatric services are generally lower. For both adult and paediatric acute pain presentations, the majority of centres provided care in their hospital emergency department (ED), and only a small number offered direct access to a ward (5%) or an ambulatory facility (12%). Ambulatory facilities' opening days ranged from 5 – 7, with 64% only operating during standard hours. Access to an acute pain service (APS) was available in 83% and 65% for adult and paediatric departments respectively. Generic pain protocols were available in 50 services. The protocols vary, but the most common analgesia prescribed in adults was morphine (oral or subcutaneous). In children, morphine (oral or intranasal) was widely used. Individual pain protocols were used in 61% of responding centres. The NICE standard '<30 minutes time to first analgesia' were not met in the majority of centres (range 30–60, outliers 80–128 min). Overall, the time to first analgesia was lower in services with ambulatory care facilities. The length of stay ranged between 3–5 days. Between 1–5% of the patients experienced a prolonged admission (>21 days). Frequent re-admissions occurred in 2–10% of the patient population (≥3 admissions/year). Education and teaching sessions were infrequently delivered for ED consultants, ED nurses, Acute Medicine consultants and pharmacists (30%, 40%, 21% and 5%).

Summary: Hospital management of acute sickle pain is a significant challenge to NHS services and needs to be re-evaluated.

Conclusion: The questionnaire results will inform the objectives and work plans of four working groups within the NSPG (acute pain, chronic pain, education and research). In order to develop national policies, it will be necessary to generate evidence through a more detailed audit of outcomes in scenarios of best practices identified here.

Summary: Hospital management of acute sickle pain is a significant challenge to NHS services and needs to be re-evaluated at local and national level. Despite publication of NICE guidelines in 2012, few services in the NHS are able to consistently provide timely pain relief. The range of policies for analgesia management is surprisingly broad.

The availability of ambulatory care in some centres could function as an exemplar for national practice. There may be alternative models of care which could be effective. Patients with frequent attendance and prolonged hospital stay are present in most centres and, although relatively small as a proportion of the service, are especially challenging to manage. The management of these patients requires a multidisciplinary approach and the development of national guidance, as often this is outside the expertise of haematologists. This may be helpful in improving outcomes in this patient cohort.

The infrequent delivery of teaching reveals the need for regular local and national mandatory educational training of all ED staff providing care to SCD patients during acute presentations.

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