Appendix C Guideline scope

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

SCOPE

1 Guideline title

Sickle cell acute painful episode: management of an acute painful sickle cell episode in hospital

1.1 Short title

Sickle cell acute painful episode

2 The remit

The Department of Health has asked NICE: 'To produce a clinical guideline on the management of sickle cell crisis in hospital.'

The scope refers to sickle cell crisis as an acute painful sickle cell episode.

3 Clinical need for the guideline

3.1 Epidemiology

a) Sickle cell disease (SCD) is the name given to a group of lifelong inherited conditions of haemoglobin formation. Most people affected are of African or African-Caribbean origin, although the sickle gene is found in all ethnic groups. Sickle cell disease can have a significant impact on morbidity and mortality.

b) Acute painful sickle cell episodes are caused by the sickling process. The red blood cells in people with sickle cell disease behave differently under a variety of conditions, including dehydration, low oxygen and elevated temperature. Changes in any of these conditions may cause them to block small vessels and

cause tissue infarction. Crises are often unpredictable and pain may vary in intensity but can be excruciating. Repeated crises may result in organ damage.

c) It is estimated that there are between 12,500 and 15,000 people with sickle cell disease in the UK. The National Haemoglobinopathy Registry aims to improve patient care and will provide more accurate information on the number and geographical distribution of patients in the future. The prevalence of the disease is increasing because of immigration into the UK and new births. The National Sickle Cell and Thalassaemia newborn screening programme also means that more cases are being diagnosed.

d) The distribution of disease reflects that of the multi-ethnic population in the UK: about two thirds of people with sickle cell disease live in London, with the majority of others in major urban areas such as the West Midlands and Manchester. The geographical distribution of sickle cell disease is widening through immigration into other parts of the UK and the increasing mobility of the population.

3.2 Current practice

a) The management of painful sickle cell episodes is variable throughout the UK and this is a frequent source of complaints from patients. Common problems are: unacceptable delays in receiving analgesia, insufficient or excessive doses, inappropriate analgesia, and stigmatising the patient as drug seeking.

b) The approach to pain management follows the WHO stepladder of non-opioid and opioid analgesia. Treatment begins with non-opioids such as paracetamol and progresses though to weak opioids such as codeine and then stronger opioids such as morphine until the pain is controlled.

c) There is guidance available from the British Committee for Standards in Haematology (2003) and Sickle Cell Society (2008) relating to the management of acute pain. There is also a guideline for clinical care in children published by the NHS Sickle Cell and Thalassaemia Screening Programme and The Sickle Cell Society (2010). Recommendations from these guidelines cover the type and timing of analgesia, assessment and monitoring of pain and other physiological measures, and the teams involved in caring for patients with an acute painful sickle cell episode.

4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections. The guideline will cover management from the point at which it is suspected that the patient is having an acute painful sickle cell episode until the pain is under control. This will be separated into defined time periods as appropriate.

4.1 Population

4.1.1 Groups that will be covered

a) Adults, children and young people with any genotype for sickle cell disease who present with an acute painful sickle cell episode.

b) Within this population, consideration will be given to the specific needs of:

- pregnant women, and
- age-specific subgroups.

4.1.2 Groups that will not be covered

a) People who are sickle cell carriers.

b) People who present with a crisis that is not associated with an acute painful sickle cell episode (such as aplastic crisis).

4.2 Healthcare setting

a) In-hospital settings and specialist centres in the NHS.

4.3 Clinical management

4.3.1 Key clinical issues that will be covered

a) Pharmacological interventions that are used to manage acute painful episodes in hospital. This includes all types of analgesia, including NSAIDs, non-opioids, weak opioids and strong opioids. This also includes oxygen, nitrous oxide and prescribed fluids. Note that guideline recommendations will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will assume that prescribers will use a drug's summary of product characteristics to inform their decisions for individual patients.

b) Choice, timing and route of analgesia, including patient-controlled analgesia.

c) When and how often pain and physiological assessments are carried out for monitoring purposes.

d) Non-pharmacological interventions that are used to manage acute painful episodes in hospital.

e) Clinical signs and symptoms to identify patients who are likely to have acute complications associated with a painful sickle cell episode.

f) Optimal clinical setting for managing episodes of acute pain.

g) Skills and knowledge of healthcare professionals and teams providing care.

h) The specific information and support needs of adults and children and young people with an acute painful sickle cell episode, and their parents/carers and families, in relation to pain management.

4.3.2 Clinical issues that will not be covered

a) Managing chronic pain.

b) Preventing an acute painful sickle cell episode.

c) Formal diagnostic investigations to confirm acute complications.

d) Managing acute complications.

e) Managing side effects associated with interventions used to manage acute pain.

f) Sickle cell episodes not associated with acute pain.

g) Co-medications, unless they are used to manage acute pain.

4.4 Main outcomes

a) Survival.

b) Intensity and duration of pain using validated and age-appropriate pain rating scales (this will include parental and healthcare professional assessment for children).

c) Rates of adverse events that are associated with interventions to manage acute painful episodes in hospital.

d) Development of acute complications.

e) Patient and carer satisfaction or experience of pain management.

f) Health-related quality of life.

g) Resource use and cost.

4.5 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY), and the costs considered will usually only be from an NHS and personal social services (PSS) perspective. Further detail on the methods can be found in 'The guidelines manual' (see ‘Further information’).

The key health economic question for this guideline appears to be the cost effectiveness of different pharmacological strategies for managing an acute painful sickle cell episode. The strategies evaluated will depend on the availability of data on which to base estimates of costs and effects.

Further cost effectiveness analysis will be considered if any additional questions are identified during guideline development.

4.6 Status

4.6.1 Scope

This is the final scope.

4.6.2 Timing

The development of the guideline recommendations will begin in August 2011.

5 Related NICE guidance

5.1 Published guidance

- Antenatal care. NICE clinical guideline 62 (2008). Available from www.nice.org.uk/guidance/CG62

- Intrapartum care. NICE clinical guideline 55 (2007). Available from www.nice.org.uk/guidance/CG55
- Acutely ill patients in hospital. NICE clinical guideline 50 (2007). Available from www.nice.org.uk/guidance/CG50
- Depression in adults with a chronic physical health problem. NICE clinical guideline 91 (2009). Available from www.nice.org.uk/guidance/CG91

5.2 Guidance under development

NICE is currently developing the following related guidance (details available from the NICE website).

- Opioids in palliative care. NICE clinical guideline. Publication date to be confirmed.

6 Further information

Information on the guideline development process is provided in:

- ‘How NICE clinical guidelines are developed: an overview for stakeholders' the public and the NHS’
- ‘The guidelines manual’.

These are available from the NICE website (www.nice.org.uk/guidelinesmanual). Information on the progress of the guideline will also be available from the NICE website (www.nice.org.uk).

Appendix D How this guideline was developed

This guideline was developed in accordance with the process for short clinical guidelines set out in 'The guidelines manual' (2009) (see www.nice.org.uk/GuidelinesManual). There is more information about how NICE clinical guidelines are developed on the NICE website (www.nice.org.uk/HowWeWork). A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' (fourth edition, published 2009), is available from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1739).

Additional methods used

For the review question addressing clinical signs and symptoms of acute complication, a modified approach was used with GRADE. This is because GRADE has not been developed for use with prognostic studies, therefore methods based on the use of GRADE for diagnostic studies were applied. The same criteria (risk of bias, inconsistency, imprecision and indirectness) were used to downgrade the quality of the evidence. In terms of study design, prospective studies were started with a high-quality rating, whereas retrospective studies were started with a low-quality rating and downgraded as appropriate. This is because there is a higher risk of information bias associated with retrospective study designs. Quality ratings were further downgraded for risk of bias if there was evidence of selection bias or other bias (these were assessed in accordance with the checklist for prognostic studies in the guidelines manual, 2009). Inconsistency was assessed by examining unexplained differences in estimates of effect. In this case, a range of different estimates of effect were reported including diagnostic accuracy statistics, statistical measures of association or adjusted OR's from multivariate regression analyses. Indirectness was assessed by examining any important differences in population, prognostic factor or outcome of the included evidence compared with those whom the recommendation is intended. Imprecision was assessed by examining the sample size or the 95% confidence intervals around the estimate of effect. Although GRADE provides rules of thumb when assessing imprecision in intervention questions, (i.e.

where the total sample size is less than 400, the event rate is less than 300 or the 95% confidence intervals cross the thresholds for appreciable benefit or harm or the minimal important difference) these may not be directly applicable to prognostic studies. For this review question the evidence was downgraded for imprecision where 95% confidence intervals (if reported or calculated) were wide. This criterion was met if the interval was not narrow enough to support a recommendation or the final recommendation would change if the effect estimate was equal to the lower 95% boundary. Where no confidence intervals were reported, small sample sizes was used as a criterion for downgrading. As sample sizes were small for all included studies (i.e. less than 400) the evidence was generally downgraded for imprecision even if confidence intervals were relatively narrow.

For the review question addressing the information and support needs of patients and their carers, GRADE was not used to present the evidence as GRADE methodology has not yet been adapted for use with qualitative studies. Alternatively a thematic analysis was undertaken. All of the included studies were initially screened to identify common key themes and issues relating to patient experiences during admission for an acute painful sickle cell episode. The evidence was then further explored to identify common subthemes across all included papers. All papers were then re-examined to ensure that all relevant key themes and subthemes were extracted. There is currently no checklist available for the assessment of survey or questionnaire designs. Therefore a checklist originally published in the British Medical Journal was modified to aid the quality assessment of these studies. (See appendix E for a copy of this checklist.)

Search strategies

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches, following the methods described in ‘The guidelines manual' (2009). The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Development Group and Short Clinical Guidelines Technical Team.

The search strategies for the review questions were developed by the Information Services Team with advice from the Short Clinical Guidelines Technical Team. Structured questions were developed using the PICO (population, intervention, comparison, outcome) model and translated into search strategies using subject heading and free text terms. The strategies were run across a number of databases with no date restrictions imposed on the searches.

The NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED) were searched for economic evaluations. Search filters for economic evaluations and quality of life studies were used on bibliographic databases. There were no date restrictions imposed on the searches.

Guideline Development Group members were also asked to alert the Short Clinical Guidelines Technical Team to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Scoping searches

Scoping searches were undertaken on the following websites and databases (listed in alphabetical order) in April 2011 to provide information for scope development and project planning. Browsing or simple search strategies were employed.

Guidelines/websites	**Systematic reviews/economic evaluations**
African Health Policy Network American Academy of Pain Medicine American Pain Society American Sickle Cell Anemia Association American Society of Hematology American Society of Pediatric Hematology/Oncology British Medical Association (BMA) British Pain Society British Society for Haematology British Committee for Standards in Haematology College of Emergency Medicine	BMJ Clinical Evidence Cochrane Database of Systematic Reviews (CDSR) Database of Abstracts of Reviews of Effects (DARE) Health Economic Evaluations Database (HEED) Health Technology Assessment (HTA) Database NHS Economic Evaluation Database (NHS EED) NIHR Service Delivery and Organisation programme (NIHR SDO)

Department of Health Clinical Knowledge Summaries - CKS Guidelines International Network (GIN) National Confidential Enquiry into Patient Outcome and Death National Institute for Health and Clinical Excellence (NICE) - published & in development National Institute for Health and Clinical Excellence (NICE) - Topic Selection National Institute for Innovation and Improvement NHS Evidence NHS Sickle Cell & Thalassaemia Screening Programme Organisation for Sickle Cell Anaemia Research and Thalassaemia Support (OSCAR) Royal Colleges Scottish Intercollegiate Guidelines Network (SIGN) Sickle Cell Disease Association of America Sickle Cell Society Sickle Cell Information Center Society for Acute Medicine UK Forum on Haemoglobin Disorders World Health Organisation	National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme TRIP Database

Main searches

The following sources were searched for the topics presented in the sections below.

- CINAHL (HDAS)
- Cochrane Database of Systematic Reviews – CDSR (Wiley)
- Cochrane Central Register of Controlled Trials – CENTRAL (Wiley)
- Database of Abstracts of Reviews of Effects – DARE (Wiley and CRD website)
- Health Technology Assessment Database – HTA (Wiley and CRD website)
- EMBASE (Ovid)

- MEDLINE (Ovid)
- MEDLINE In-Process (Ovid)
- PSYCINFO (Ovid)

Systematic reviews and mapping searches

The searches were conducted during May 2011. The aim of the searches was to identify evidence for all the review questions of the 'Sickle cell acute painful episode' clinical guideline

The MEDLINE search strategy is presented below. It was translated for use in all of the other databases.

Ovid MEDLINE <1948 to May Week 2 2011>

1 exp Anemia, Sickle Cell/ (15887)
2 exp Pain/ (264029)
3 Acute Disease/ (168610)
4 (pain$ or acute$ or cris$ or episode$).tw.
5 or/2-4
6 1 and 5
7 (sickl$ adj10 (pain$ or acute$ or cris$ or episode$)).tw.
8 6 or 7

Economic search

The following sources were searched to identify economic evaluations and quality of life data featuring patients with acute painful sickle cell episode.

- NHS Economic Evaluation Database – NHS EED (Wiley and CRD website
- Health Economic Evaluations Database – HEED (Wiley)
- Embase (Ovid)
- MEDLINE (Ovid)
- MEDLINE In-Process (Ovid)

Ovid MEDLINE <1950 to March Week 4 2011>

1 exp Anemia, Sickle Cell/
2 Hemoglobin, Sickle/

3 sickl$.tw.

4 or/1-3

Health economics and quality of life methodological search filters

The MEDLINE economic evaluations and quality of life search filters are presented below. They were translated for use in the MEDLINE In-Process and Embase databases.

Economic evaluations

1 Economics/

2 exp "Costs and Cost Analysis"/

3 Economics, Dental/

4 exp Economics, Hospital/

5 exp Economics, Medical/

6 Economics, Nursing/

7 Economics, Pharmaceutical/

8 Budgets/

9 exp Models, Economic/

10 Markov Chains/

11 Monte Carlo Method/

12 Decision Trees/

13 econom$.tw.

14 cba.tw.

15 cea.tw.

16 cua.tw.

17 markov$.tw.

18 (monte adj carlo).tw.

19 (decision adj2 (tree$ or analys$)).tw.

20 (cost or costs or costing$ or costly or costed).tw.

21 (price$ or pricing$).tw.

22 budget$.tw.

23 expenditure$.tw.

24 (value adj2 (money or monetary)).tw.

25 (pharmacoeconomic$ or (pharmaco adj economic$)).tw.

26 or/1-25

Quality of life

1 "Quality of Life"/

2 quality of life.tw.

3 "Value of Life"/

4 Quality-Adjusted Life Years/

5 quality adjusted life.tw.

6 (qaly$ or qald$ or qale$ or qtime$).tw.

7 disability adjusted life.tw.

8 daly$.tw.

9 Health Status Indicators/

10 (sf36 or sf 36 or short form 36 or shortform 36 or sf thirtysix or sf thirty six or shortform thirtysix or shortform thirty six or short form thirtysix or short form thirty six).tw.

11 (sf6 or sf 6 or short form 6 or shortform 6 or sf six or sfsix or shortform six or short form six).tw.

12 (sf12 or sf 12 or short form 12 or shortform 12 or sf twelve or sftwelve or shortform twelve or short form twelve).tw.

13 (sf16 or sf 16 or short form 16 or shortform 16 or sf sixteen or sfsixteen or shortform sixteen or short form sixteen).tw.

14 (sf20 or sf 20 or short form 20 or shortform 20 or sf twenty or sftwenty or shortform twenty or short form twenty).tw.

15 (euroqol or euro qol or eq5d or eq 5d).tw.

16 (qol or hql or hqol or hrqol).tw.

17 (hye or hyes).tw.

18 health$ year$ equivalent$.tw.

19 utilit$.tw.

20 (hui or hui1 or hui2 or hui3).tw.

21 disutili$.tw.

22 rosser.tw.

23 quality of wellbeing.tw.

24 quality of well-being.tw.

25 qwb.tw.

26 willingness to pay.tw.

27 standard gamble$.tw.

28 time trade off.tw.

29 time tradeoff.tw.

30 tto.tw.

31 or/1-30

Review questions and review protocols

Review questions

- Review question 1: How should the acute painful episode be managed using pharmacological interventions?
- Review question 2: How should the acute painful episode be managed using non-pharmacological interventions?
- Review question 3: What are the clinical signs and symptoms to identify patients who are likely to have an acute complication?
- Review question 4: Where should the acute painful episode should be managed?
  - What skills are required by healthcare professionals and teams providing care?
- Review question 5: What information do people need during an acute painful sickle cell episode?

Review protocols

	Details	Additional comments	Status
Review question 1	How should the acute painful episode be managed using pharmacological interventions?		The protocol was amended post GDG 1 to refer to the management of the 'acute painful episode' rather than 'acute pain'
Objectives	To identify how pharmacological interventions should be used to manage an acute painful episode This will include; Timing and choice of drugs until the patient has been discharged What route should these drugs be given by?		

	Should patient controlled analgesia (PCA) be used? When and how often should patients be monitored for pain and physiological measures?		
Language	English		
Study design	RCTs and systematic reviews		
Status	Published papers (full papers only)		
Population	Adults and children and young people with a diagnosis of sickle cell disease who present with an acute painful sickle cell episode Within this population, pregnant women will be considered as a sub-group as appropriate Consideration will also be given to age-specific sub groups as appropriate		
Intervention	pharmacological interventions to manage an acute painful episode	Search terms: any drugs used for pain relief and to include the following; NSAIDs and non-opioids: paracetamol, aspirin, nefopam, ibuprofen, diflunisal, ketorolac, diclofenac, amytripyline, entonox, ketamine Strong opiates/opioids: morphine, buprenorphine, dipipanone, diamorphine, fentanyl, alfentanil, remifentanil, methadone, oxycodone, papaveretum, pethidine, pentazocine, tramadol	

		Weak opiates/opioids: codeine, dihydrocodeine, meptazinol Corticosteroids: dexamethasone, methylprednisolone Other: patient controlled analgesia (PCA), gabapentin, pregabalin, oxygen and fluids (general supportive care)	
Comparator	placebo or other treatment (including combinations)		
Outcomes	Intensity and duration of pain (using validated and age appropriate scales) Adverse events associated with pain management Survival Health related quality of life Resource use and cost		
Other criteria for inclusion/exclusion of studies	Include: RCTs comparing pharmacological intervention for acute painful episodes with placebo or other treatment Any pharmacological intervention used to manage the acute painful episode all secondary and tertiary settings (inpatient and outpatient) any follow-up period open label studies patients who experience an acute painful episode as an inpatient (e.g. post surgery)	Any additional criteria applied – duration of follow up etc	

	Exclude: drugs used to reduce the incidence of painful sickle cell episodes management of the acute painful episode in other settings (e.g. community, pre hospital setting) co-medications (unless used to manage the acute painful episode) chronic pain (unless accompanied by acute pain)		
Search strategies	RCTs and systematic reviews		
Review strategies	The NICE methodology checklist for RCTs will be used as a guide to appraise the quality of individual studies Data on all included studies will be extracted into evidence tables Where statistically possible, a meta-analytical approach will be used to give an overall summary effect All key outcomes from evidence will be presented in GRADE profiles or modified profiles and further summarized in evidence statements Sub-group analysis will be undertaken for children and pregnant woman where appropriate		
Identified key studies	Dunlop & Bennett (2009). Pain management for sickle cell disease in children and adults. Cochrane review. This included 10 primary studies.		

	Details	**Additional comments**	**Status**
Review question 2	How should the acute painful episode be managed using non-pharmacological interventions?		
Objectives	What non-pharmacological interventions should be used to manage the acute painful episode (if any)?		

	At what point should these interventions be used?		
Language	English		
Study design	RCTs and systematic reviews		
Status	Published papers (full papers only)		
Population	Adults and children and young people with a diagnosis of sickle cell disease who present with an acute painful sickle cell episode Within this population, pregnant women will be considered as a sub-group as appropriate Consideration will also be given to age-specific sub groups as appropriate		
Intervention	non-pharmacological interventions to manage an acute painful episode	Search terms (please restrict to the following): distraction techniques, acupuncture, TENs and heat therapy, mobilization/immobilisation	The searches that were carried out were broad and no restrictions were made on the type of intervention.
Comparator	placebo or other treatment (including combinations)		
Outcomes	Intensity and duration of pain (using validated and age appropriate scales) Adverse events associated with pain management Survival Health related quality of life Resource use and cost		
Other criteria for inclusion/exclusion of studies	Include: RCTs comparing non-pharmacological intervention for managing the acute painful episode with placebo or other treatment Non-pharmacological interventions may be self-administered all secondary and tertiary settings (inpatient and outpatient)	Any additional criteria applied – duration of follow up etc	

	any follow-up period patients who experience an acute painful episode as an inpatient (e.g. post surgery) Exclude: management of the acute painful episode in other settings (e.g. community) co-medications (unless specifically used to manage the acute painful episode) chronic pain (unless accompanied by acute pain)		
Search strategies	RCTs and systematic reviews		
Review strategies	The NICE methodology checklist for RCTs will be used as a guide to appraise the quality of individual studies Data on all included studies will be extracted into evidence tables Where statistically possible, a meta-analytical approach will be used to give an overall summary effect All key outcomes from evidence will be presented in GRADE profiles or modified profiles and further summarized in evidence statements Sub-group analysis will be undertaken for children and pregnant woman where appropriate		
Identified key studies	N/A		

	Details	**Additional comments**	**Status**
Review question 3	What are the clinical signs and symptoms to identify patients who are likely to have an acute complication?		
Objectives	Are there any specific signs and symptoms that can predict patients		

	who are high risk of developing acute complications? Does identifying acute complications at an early stage increase survival?		
Language	English		
Study design	Prognostic (cohort, case-control etc)		
Status	Published papers (full papers only)		
Population	Adults and children and young people with a diagnosis of sickle cell disease who present with an acute painful sickle cell episode Within this population, pregnant women will be considered as a sub-group as appropriate Consideration will also be given to age-specific sub groups as appropriate		
Prognostic factor	clinical signs and symptoms or risk factors to predict the development of acute complications		
Comparator	diagnosis of acute complication		
Outcomes	Development of acute complications Survival Health related quality of life	Search terms of acute complications: Acute Chest Syndrome (ACS), acute abdomen (including gall bladder disease), acute anaemia, acute splenic and hepatic sequestration, acute neurological symptoms (including acute stroke), suspected acute osteomyelitis, acute renal disease, acute priapism, febrile patients (including infection)	

Other criteria for inclusion/exclusion of studies	Include: patients with diagnosis of an acute complication associated with painful sickle cell episode focus on risk factors for acute complications in patients with acute painful sickle cell episode any prognostic design laboratory markers as risk factors for acute complications) Exclude: focus on risk factors for acute complications in patients in a 'steady state' of sickle cell (i.e. not experiencing an acute painful episode) focus on management of acute complications narrative reviews of clinical characteristics case studies and case series prevention of acute complications focus on formal diagnostic investigations to confirm an acute complication	Any additional criteria applied – duration of follow up etc	
Search strategies	No restriction on study design		
Review strategies	Appropriate NICE methodology checklists (depending on the study design) will be used as a guide to appraise the quality of individual studies Data on all included studies will be extracted into evidence tables Where statistically possible, a meta-analytical approach will be used to give an overall summary effect All key outcomes from evidence will be presented in GRADE profiles or modified profiles and further summarized in evidence statements Sub-group analysis will be undertaken for children when appropriate		
Identified key studies	N/A		

	Details	Additional comments	Status
Review question 4	Where should an acute painful episode be managed? What skills/ knowledge are required by healthcare professionals and teams providing care?		
Objectives	To identify the most appropriate setting and skills for managing an acute painful episode		
Language	English		
Study design	RCTs, systematic reviews, cohort studies, case-control studies		
Status	Published papers (full papers only)		
Population	Adults and children and young people with a diagnosis of sickle cell disease who present with an acute painful sickle cell episode Within this population, pregnant women will be considered as a sub-group as appropriate Consideration will also be given to age-specific sub groups as appropriate		
Intervention	management of an acute painful episode in specialist settings (including secondary care with specialist input)		
Comparator	management of an acute painful episode in secondary care (without specialist sickle cell input)		
Outcomes	Adverse events associated with pain management Survival Health related quality of life Resource use and cost		
Other criteria for inclusion/exclusion of studies	Include: Any study design focusing on organisation of care or skills/ knowledge of healthcare professionals Exclude:		

	management of an acute painful episode in other settings (e.g. community) opinion piece/editorial/letter focus on clinical pathway without reference to organisation of care or skills/ knowledge of healthcare professionals		
Search strategies	No restriction on study design		
Review strategies	Appropriate NICE methodology checklists (depending on the study design) will be used as a guide to appraise the quality of individual studies Data on all included studies will be extracted into evidence tables Where statistically possible, a meta-analytical approach will be used to give an overall summary effect All key outcomes from evidence will be presented in GRADE profiles or modified profiles and further summarized in evidence statements Sub-group analysis will be undertaken for children when appropriate		
Identified key studies	N/A		

	Details	**Additional comments**	**Status**
Review question 5	What information do people need during an acute painful sickle cell episode and at discharge?		The review question was amended post GDG 1 to specifically cover both discharge information requirements and those required

			during the episode
Objectives	To identify the information and support needs of patients and their carers during an episode of acute painful sickle cell		
Language	English		
Study design	RCT, cohort studies, case-control studies, qualitative studies		
Status	Published papers (full papers only)		
Population	Adults and children and young people with a diagnosis of sickle cell disease who present with an acute painful sickle cell episode Within this population, pregnant women will be considered as a sub-group as appropriate Consideration will also be given to age-specific sub groups as appropriate		
Intervention	information/support needs of patients and their family/carers		
Comparator	standard care		
Outcomes	Patient satisfaction or experience of pain management Health related quality of life		
Other criteria for inclusion/exclusion of studies	Include: any patient education intervention related to an acute painful sickle cell episode focus on patient experiences during inpatient management of acute painful episode focus on identified needs/information during inpatient management of acute painful episode Exclude: not focused on patient experience or needs		
Search strategies	No restriction on study design		

Review strategies	Appropriate NICE methodology checklists (depending on the study design) will be used as a guide to appraise the quality of individual studies Data on all included studies will be extracted into evidence tables Where statistically possible, a meta-analytical approach will be used to give an overall summary effect All key outcomes from evidence will be presented in GRADE profiles or modified profiles and further summarized in evidence statements Sub-group analysis will be undertaken for children when appropriate		
Identified key studies	N/A		

Excluded studies

List of excluded studies for review questions 1 and 2: Pharmacological and non-pharmacological management

Vandy, B.L. & Smith, W.R. 2010. Evidence-based mini-review: Are systemic corticosteroids an effective treatment for acute pain in sickle cell disease? [Review]. Hematology, 2010, 416-417

Ref ID: 7

EXCLUDE-REVIEW

Ballas, S.K., Bauserman, R.L., McCarthy, W.F., Castro, O.L., Smith, W.R., Waclawiw, M.A., & Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia 2010. Hydroxyurea and acute painful crises in sickle cell anemia: effects on hospital length of stay and opioid utilization during hospitalization, outpatient acute care contacts, and at home. Journal of Pain & Symptom Management, 40, (6) 870-882

Ref ID: 24

EXCLUDE-TREATMENT NOT GIVEN IN-HOSPITAL

Edwards, L.Y. & Edwards, C.L. 2010. Psychosocial treatments in pain management of sickle cell disease. [Review]. Journal of the National Medical Association, 102, (11) 1084-1094

Ref ID: 55

EXCLUDE-REVIEW

Oniyangi, O. & Cohall, D.H. 2010. Phytomedicines (medicines derived from plants) for sickle cell disease. [Review][Update of Cochrane Database Syst Rev. 2004;(3):CD004448; PMID: 15266534]. Cochrane Database of Systematic Reviews (10) CD004448

Ref ID: 77

EXCLUDE-NOT IN-HOSPITAL TREATMENT OF ACUTE PAINFUL EPISODE (FOCUS ON PREVENTION)

Mousa, S.A., Al, M.A., Al, S.F., Al, J.S., Nasrullah, Z., Al, S.H., Alabdullatif, A., Al, S.M., Al, Z.H., Hegazi, M., Al, M.A., Alsulaiman, A., Omer, A., Al, K.S., Tarawa, A., Al, O.F., & Qari, M. 2010. Management of painful vaso-occlusive

crisis of sickle-cell anemia: consensus opinion. [Review]. Clinical & Applied Thrombosis/Hemostasis, 16, (4) 365-376
Ref ID: 82
EXCLUDE-REVIEW

Barakat, L.P., Schwartz, L.A., Salamon, K.S., & Radcliffe, J. 2010. A family-based randomized controlled trial of pain intervention for adolescents with sickle cell disease. Journal of Pediatric Hematology/Oncology, 32, (7) 540-547
Ref ID: 87
EXCLUDE-PATIENTS NOT HAVING PAINFUL EPISODE

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Ref ID: 1915
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EXCLUDE-OVERVIEW

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EXCLUDE-OPINION PIECE

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EXCLUDE-MAGAZINE ARTICLE

Nichols, R. 1996. Pain control. Pain during sickle-cell crisis. American Journal of Nursing, 96, (1) 59-61
Ref ID: 8513
EXCLUDE-OPINION PIECE

1994. Corticosteroid may cut sickle cell pain. RN, 57, (7) 78-79
Ref ID: 8534
EXCLUDE-EDITORIAL

Brookoff, D. 1992. A protocol for defusing sickle cell crisis. Emergency Medicine (00136654), 24, (1) 130-137
Ref ID: 8553

EXCLUDE-PROTOCOL

Eke, F.U., Obamyonyi, A., Eke, N.N., & Oyewo, E.A. 2000. An open comparative study of dispersible piroxicam versus soluble acetylsalicylic acid for the treatment of osteoarticular painful attack during sickle cell crisis. Tropical Medicine & International Health, 5, (2) 81-84
Ref ID: 1609

EXCLUDE-PIROXICAM NOT USED FOR ACUTE PAINFUL EPISODES IN UK

Perlin, E., Finke, H., Castro, O., Bang, K.M., Rana, S., Taylor, R., Addo, K., Adir, J., Miller, A.K., Elemihe, U.N., & Curry, C.E. 1988. Treatment of sickle cell pain crisis. A clinical trial of diflunisal (Dolobid). Clinical Trials Journal, 25, (4) 254-264
Ref ID: 7202
EXCLUDE-UNLICENCED DRUG

Uzun, B., Kekec, Z., & Gurkan, E. 2010. Efficacy of tramadol vs meperidine in vasoocclusive sickle cell crisis. American Journal of Emergency Medicine, 28, (4) 445-449
Ref ID: 131
EXCLUDE-BOTH TRAMADOL AND PETHIDINE ARE NOT USED IN UK

Full list of excluded papers for review question 3: Clinical signs and symptoms of acute complications

Abramson N. Sickle cell disease with abdominal pain. Blood 2007;109(3):858.
Reason for exclusion: Case series or case study

Ahmed S., Siddiqui A.K., Siddiqui R.K., Kimpo M., Russo L., Mattana J. Acute pancreatitis during sickle cell vaso-occlusive painful crisis. American Journal of Hematology 2003;73(3):190-93.
Reason for exclusion: Case series or case study

Ahmed S.G., Ibrahim U.A., Hassan A.W. Hematological parameters in sickle cell anemia patients with and without priapism. Annals of Saudi Medicine 2006;26(6):439-43.
Reason for exclusion: Not all patients with acute episode

Ajayi A.O., Bojuwoye B.J., Braimoh K., Ndububa D.A. Clinical and laboratory indices of cholelithiasis in adult Nigerians with sickle-cell anaemia. Tropical Doctor 2006;36(1):41-42.
Reason for exclusion: Not all patients with acute episode

Akakpo-Numado G.K., Gnassingbe K., Abalo A., Boume M.A., Sakiye K.A., Tekou H. Locations of osteomyelitis in children with sickle-cell disease at Tokoin teaching hospital (Togo). Pediatric Surgery International 2009;25(8):723-26.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Akinola N.O., Bolarinwa R.A., Faponle A.F. The import of abdominal pain in adults with sickle cell disorder. West African Journal of Medicine 2009;28(2):83-86.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Al-Dabbous I.A. Acute chest syndrome in sickle cell disease in Saudi Arab Children in the Eastern Province. Annals of Saudi Medicine 2002;22(3-

4):167-71.
Reason for exclusion: Not all patients with acute episode

Al-Malki T.A. & Ibrahim A.H. Common hepatic duct perforation in a sickle cell disease child. Annals of Saudi Medicine 2004;24(1):43-45.
Reason for exclusion: Case series or case study

Al-Mendalawi M.D. Anemic crisis due to Mycoplasma pneumoniae complication in sickle cell patients. Saudi Medical Journal 2009;30(8):1105.
Reason for exclusion: Editorial/letter

Al-Mulhim A.S. Appendectomy during pregnancy in sickle cell disease patients. Saudi Journal of Gastroenterology 2008;14(3):114-17.
Reason for exclusion: Not all patients with acute episode

Al-Nazer M.A., Al-Saeed H.H., Al-Salem A.H. Acute appendicitis in patients with sickle cell disease. Saudi Medical Journal 2003;24(9):974-77.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Alonso M.H. Gall bladder abnormalities in children with sickle cell disease: Management with laparoscopic cholecystectomy. Journal of Pediatrics 2004;145(5):580-81.
Reason for exclusion: Editorial/letter

Al-Rimawi H.S., Abdul-Qader M., Jallad M.F., Amarin Z.O. Acute splenic sequestration in female children with sickle cell disease in the North of Jordan. Journal of Tropical Pediatrics 2006;52(6):416-20.
Reason for exclusion: Not all patients with acute episode

Al-Trabolsi H.A. & Alshehri M. Acute chest syndrome in children with sickle cell disease: Saudi Arabian experience. Current Pediatric Research 2005;9(1-2):23-26.
Reason for exclusion: Not all patients with acute episode

Al-Trabolsi H.A. & Alshehri M. Acute chest syndrome in children with sickle cell disease. Bahrain Medical Bulletin 2005;27(3):119-22.

Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Ambrusko S.J., Gunawardena S., Sakara A., Windsor B., Lanford L., Michelson P., Krishnamurti L. Elevation of tricuspid regurgitant jet velocity, a marker for pulmonary hypertension in children with sickle cell disease. Pediatric Blood & Cancer 2006;47(7):907-13.
Reason for exclusion: Not all patients with acute episode

Araujo A.N. Acute splenic sequestration in children with sickle cell anemia. Jornal de Pediatria ;85(4):373-Aug.
Reason for exclusion: Editorial/letter

Arkuszewski M., Melhem E.R., Krejza J. Neuroimaging in assessment of risk of stroke in children with sickle cell disease. [Review]. Advances in Medical Sciences 2010;55(2):115-29.
Reason for exclusion: Review

Aslam A.K., Rodriguez C., Aslam A.F., Vasavada B.C., Khan I.A. Cardiac troponin I in sickle cell crisis. International Journal of Cardiology 2009;133(1):138-39.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

AYCOCK E.K. & WESTON W. Jr. Coexistent sickle cell disease and acute rheumatic fever. Journal - South Carolina Medical Association 1960;56:89-92.
Reason for exclusion: Inaccessible

Bakhotmah M.A. Symptomatic cholelithiasis in children: A hospital-based review. Annals of Saudi Medicine 1999;19(3):251-52.
Reason for exclusion: Not all patients with acute episode

Ballas S.K. Neurocognitive complications of sickle cell anemia in adults. JAMA 2010;303(18):1862-63.
Reason for exclusion: Editorial/letter

Ballas S.K., Files B., Luchtman-Jones L., Benjamin L., Swerdlow P., Hilliard L., et al. Secretory phospholipase A2 levels in patients with sickle cell disease and acute chest syndrome. Hemoglobin 2006;30(2):165-70.
Reason for exclusion: Focus on diagnosis

Bargoma E.M., Mitsuyoshi J.K., Larkin S.K., Styles L.A., Kuypers F.A., Test S.T. Serum C-reactive protein parallels secretory phospholipase A2 in sickle cell disease patients with vasoocclusive crisis or acute chest syndrome. Blood 2005;105(8):3384-85.
Reason for exclusion: Editorial/letter

Becton L.J., Kalpatthi R.V., Rackoff E., Disco D., Orak J.K., Jackson S.M., Shatat I.F. Prevalence and clinical correlates of microalbuminuria in children with sickle cell disease. Pediatric Nephrology 2010;25(8):1505-11.
Reason for exclusion: Not all patients with acute episode

Bernard A.W. & Venkat A. Full blood count and reticulocyte count in painful sickle crisis. Emergency Medicine Journal 2006;23(4):302-04.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Bernard A.W., Venkat A., Lyons M.S. Best evidence topic report. Full blood count and reticulocyte count in painful sickle crisis. Emergency Medicine Journal 2006;23(4):302-03.
Reason for exclusion: Review

Bernard A.W., Yasin Z., Venkat A. Acute chest syndrome of sickle cell disease. Hospital Physician 2007;43(1):15-NaN.
Reason for exclusion: Review

Bernaudin F., Strunk R.C., Kamdem A., Arnaud C., An P., Torres M., et al. Asthma is associated with acute chest syndrome, but not with an increased rate of hospitalization for pain among children in France with sickle cell anemia: a retrospective cohort study. Haematologica 2008;93(12):1917-18.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Bode-Thomas F., Hyacinth H.I., Ogunkunle O., Omotoso A. Myocardial ischaemia in sickle cell anaemia: evaluation using a new scoring system. Annals of Tropical Paediatrics 2011;31(1):67-74.
Reason for exclusion: Focus on diagnosis

Bonadio W.A. Clinical features of abdominal painful crisis in sickle cell anemia. Journal of Pediatric Surgery 1990;25(3):301-02.
Reason for exclusion: Descriptive prevalence/cross sectional study

Bono M.J. & Anglemeyer B.L. How to recognize and manage sickle cell crises. Emergency Medicine (00136654) 2005;37(12):39-44.
Reason for exclusion: Review

Boyd J.H., DeBaun M.R., Morgan W.J., Mao J., Strunk R.C. Lower airway obstruction is associated with increased morbidity in children with sickle cell disease. Pediatric Pulmonology 2009;44(3):290-96.
Reason for exclusion: Not all patients with acute episode

Caboot J.B. & Allen J.L. Pulmonary complications of sickle cell disease in children. Current Opinion in Pediatrics 2008;20(3):279-87.
Reason for exclusion: Descriptive prevalence/cross sectional study

Carvalho E.M.S., Queiroz A.M.M., Lobo C.L.C., Guimares F.A.P., Souza D.X.S., Queiroz A.P.A. No-Pain Hospital: 6th Vital sign - Pulse oximetry. It's importance in Acute Chest Syndrome (ACS). American Journal of Hematology 2009;Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Co(var.pagings)
Reason for exclusion: Prevention of acute complications

Charache S., Scott J.C., Charache P. 'Acute chest syndrome' in adults with sickle cell anemia. Microbiology, treatment, and prevention. Archives of Internal Medicine 1979;139(1):67-69.
Reason for exclusion: Descriptive prevalence/cross sectional study

CHARMOT G., REYNAUD R., BERGOT J. Cryoglobulinaemia and cold agglutinins in painful crises of sickle-cell anaemia. Lancet 1963;2(7307):540.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Clark C.G. & Boulos P.B. Abdominal pain in the overseas visitor or immigrant. Practitioner 1979;222(1330):487-96.
Reason for exclusion: Review

Cohen R.T., DeBaun M.R., Blinder M.A., Strunk R.C., Field J.J. Smoking is associated with an increased risk of acute chest syndrome and pain among adults with sickle cell disease. Blood 2010;115(18):3852-54.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Crabtree E.A., Mariscalco M.M., Hesselgrave J., Iniguez S.F., Hilliard T.J., Katkin J.P., et al. Improving care for children with sickle cell disease/acute chest syndrome. Pediatrics 2011;127(2):e480-88.
Reason for exclusion: Inaccessible

Dampier C., LeBeau P., Rhee S., Lieff S., Kesler K., Ballas S., et al. Health-related quality of life in adults with sickle cell disease (SCD): a report from the comprehensive sickle cell centers clinical trial consortium. American Journal of Hematology 2011;86(2):203-05.
Reason for exclusion: Not all patients with acute episode

Dar J., Mughal I., Hassan H., Al Mekki T.E., Chapunduka Z., Hassan I.S. Raised D-dimer levels in acute sickle cell crisis and their correlation with chest X-ray abnormalities. German Medical Science 2010;8:Doc25.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Davies S.C., Luce P.J., Win A.A., Riordan J.F., Brozovic M. Acute chest syndrome in sickle-cell disease. Lancet 1984;1(8367):36-38.
Reason for exclusion: Descriptive prevalence/cross sectional study

Davis S.J. & Safar A. Retinal arteriolar occlusions during a sickle cell crisis. New England Journal of Medicine 2010;362(6):536.
Reason for exclusion: Case series or case study

Dowling M.M., Quinn C.T., Rogers Z.R., Buchanan G.R. Acute silent cerebral infarction in children with sickle cell anemia. Pediatric Blood & Cancer 2010;54(3):461-64.
Reason for exclusion: Not all patients with acute episode

Duckworth L., Hsu L., Feng H., Wang J., Sylvester J.E., Kissoon N., et al. Physician-diagnosed asthma and acute chest syndrome: associations with NOS polymorphisms. Pediatric Pulmonology 2007;42(4):332-38.
Reason for exclusion: Not all patients with acute episode

Ebert E.C., Nagar M., Hagspiel K.D. Gastrointestinal and hepatic complications of sickle cell disease. Clinical Gastroenterology & Hepatology - 326;8(6):483-89.
Reason for exclusion: Review

El Sayed Zaki M. Clinical and hematological of parvovirus B19 infection on Egyptian children with chronic hemolytic anemia. Journal of Pediatric Infectious Diseases 2010;5(4):347-52.
Reason for exclusion: Not all patients with acute episode

Epstein F.H. Hypokalemia during sickle cell crisis. American Journal of Kidney Diseases 2008;52(1):196-97.
Reason for exclusion: Editorial/letter

Field J.J., Krings J., White N.L., Yan Y., Blinder M.A., Strunk R.C., DeBaun M.R. Urinary cysteinyl leukotriene E(4) is associated with increased risk for pain and acute chest syndrome in adults with sickle cell disease. American Journal of Hematology 2009;84(3):158-60.
Reason for exclusion: Not all patients with acute episode

Ganesh A., Al-Zuhaibi S., Pathare A., William R., Al-Senawi R., Al-Mujaini A., et al. Orbital infarction in sickle cell disease. American Journal of

Ophthalmology 2008;146(4):595-601.
Reason for exclusion: Case series or case study

George I.O., Briggs A.I.F., Ihezie C.O. Childhood osteomyelitis: A five-year analysis of patients with sickle cell anaemia in Port Harcourt, Nigeria. Pakistan Journal of Medical Sciences 2011;27(1):107-09.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Gladwin M.T. & Vichinsky E. Pulmonary complications of sickle cell disease. New England Journal of Medicine 2008;359(21):2254-65.
Reason for exclusion: Review

Goel R., Viswanathan P., Krishnamurti L. Current epidemiology and hospitalization characteristics for acute chest syndrome: A nationally representative survey. Blood 2009;Conference: 51st Annual Meeting of the American Society of Hematology, ASH New Orleans, LA United States. Conference Start: 20091205 Conference End: 20091208. Conference Publication:(var.pagings)
Reason for exclusion: Abstract only

Gumiero A.P., Bellomo-Brandao M.A., Costa-Pinto E.A. Gallstones in children with sickle cell disease followed up at a Brazilian hematology center. Arquivos de Gastroenterologia 2008;45(4):313-18.
Reason for exclusion: Not all patients with acute episode

Haddy T.B., Lusher J.M., Hendricks S., Trosko B.K. Erythropoiesis in sickle cell anaemia during acute infection and crisis. Scandinavian Journal of Haematology 1979;22(4):289-95.
Reason for exclusion: Descriptive prevalence/cross sectional study

Hagar R.W., Michlitsch J.G., Gardner J., Vichinsky E.P., Morris C.R. Clinical differences between children and adults with pulmonary hypertension and sickle cell disease. British Journal of Haematology 2008;140(1):104-12.
Reason for exclusion: Not all patients with acute episode

Hampton R.R., Balasa V., Allen Bracey S.E. Emergencies in patients with inherited hemoglobin disorders - An emergency department perspective. Clinical Pediatric Emergency Medicine 2005;6(3):138-48.
Reason for exclusion: Case series or case study

Hassell K.L., Eckman J.R., Lane P.A. Acute multiorgan failure syndrome: a potentially catastrophic complication of severe sickle cell pain episodes. American Journal of Medicine 1994;96(2):155-62.
Reason for exclusion: Descriptive prevalence/cross sectional study

Haynes Jr & Kirkpatrick M.B. The acute chest syndrome of sickle cell disease. American Journal of the Medical Sciences 1993;305(5):326-30.
Reason for exclusion: Review

Hernigou P., Daltro G., Flouzat-Lachaniette C.H., Roussignol X., Poignard A. Septic arthritis in adults with sickle cell disease often is associated with osteomyelitis or osteonecrosis. Clinical Orthopaedics & Related Research 2010;468(6):1676-81.
Reason for exclusion: Not all patients with acute episode

Hiran S. Multiorgan dysfunction syndrome in sickle cell disease. Journal of the Association of Physicians of India 2005;53:19-22.
Reason for exclusion: Descriptive prevalence/cross sectional study

Jaitly M., Mohan S., Park C.M., Anderson H.L., Cheng J.T., Pogue V.A. Hypokalemia during sickle cell crises apparently due to intermittent mineralocorticoid excess. American Journal of Kidney Diseases 2008;51(2):319-25.
Reason for exclusion: Case series or case study

Jaiyesimi O. & Kasem M. Acute chest syndrome in Omani children with sickle cell disease: epidemiology and clinical profile. Annals of Tropical Paediatrics 2007;27(3):193-99.
Reason for exclusion: Descriptive prevalence/cross sectional study

Khademian Z., Speller-Brown B., Nouraie S.M., Minniti C.P. Reversible posterior leuko-encephalopathy in children with sickle cell disease. Pediatric Blood & Cancer 2009;52(3):373-75.
Reason for exclusion: Not all patients with acute episode

Kirkham F.J. Therapy insight: stroke risk and its management in patients with sickle cell disease. Nature Clinical Practice Neurology 2007;3(5):264-78.
Reason for exclusion: Review

Knight J.S. & Lamparelli M.J. Acute abdominal pain for the general physician - Who, when and how to refer to the on-call surgeon. Acute Medicine 2005;4(1):37-39.
Reason for exclusion: Review

Koduri P.R. Acute splenic sequestration crisis in adults with sickle cell anemia. American Journal of Hematology 2007;82(2):174-75.
Reason for exclusion: Case series or case study

Kreindler J.L. Acute chest syndrome of sickle cell disease - Presentation, pathophysiology, and management. Office and Emergency Pediatrics 2000;13(5-6):175-79.
Reason for exclusion: Case series or case study

Kuypers F.A. & Styles L.A. The role of secretory phospholipase A2 in acute chest syndrome. Cellular & Molecular Biology 2004;50(1):87-94.
Reason for exclusion: Review

Kwiatkowski J.L., Zimmerman R.A., Pollock A.N., Seto W., Smith-Whitley K., Shults J., et al. Silent infarcts in young children with sickle cell disease. British Journal of Haematology 2009;146(3):300-05.
Reason for exclusion: Not all patients with acute episode

Lippi G., De Franceschi L., Salvagno G.L., Pavan C., Montagnana M., Guidi G.C. Cardiac troponin T during sickle cell crisis. International Journal of Cardiology 2009;136(3):357-58.
Reason for exclusion: Editorial/letter

Lopez B.L., Griswold S.K., Navek A., Urbanski L. The complete blood count and reticulocyte count--are they necessary in the evaluation of acute vasoocclusive sickle-cell crisis? Academic Emergency Medicine 1996;3(8):751-57.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Malik S., Duffy P., Shulte P.A. Acute splenic infarction. CMAJ Canadian Medical Association Journal 2006;175(3):244.
Reason for exclusion: Editorial/letter

Matthews M.S. Cholelithiasis: a differential diagnosis in abdominal 'crisis' of sickle cell anemia. Journal of the National Medical Association 1981;73(3):271-73.
Reason for exclusion: Case series or case study

McBurney P.G., Hanevold C.D., Hernandez C.M., Waller J.L., McKie K.M. Risk factors for microalbuminuria in children with sickle cell anemia. Journal of Pediatric Hematology/Oncology 2002;24(6):473-77.
Reason for exclusion: Not all patients with acute episode

McIntosh S., Rooks Y., Ritchey A.K., Pearson H.A. Fever in young children with sickle cell disease. Journal of Pediatrics 1980;96(2):199-204.
Reason for exclusion: Not all patients with acute episode

Mekontso Dessap A., Leon R., Habibi A., Nzouakou R., Roudot-Thoraval F., Adnot S., et al. Pulmonary hypertension and cor pulmonale during severe acute chest syndrome in sickle cell disease. American Journal of Respiratory & Critical Care Medicine 2008;177(6):646-53.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

MINTZ A.A., CHURCH G., ADAMS E.D. Relationship of cholelithiasis to sickle cell crises. Southern Medical Journal 1956;49(3):205-09.
Reason for exclusion: Case series or case study

Mock L.J. & Berman B.W. Clinical and laboratory profile of acute splenic sequestration in children with sickle cell disease. A 10-year single institutional experience. International Journal of Pediatric Hematology/Oncology 1998;5(5):287-91.
Reason for exclusion: Not all patients with acute episode

Mohtat D., Thomas R., Du Z., Boakye Y., Moulton T., Driscoll C., Woroniecki R. Urinary transforming growth factor beta-1 as a marker of renal dysfunction in sickle cell disease. Pediatric Nephrology 2011;26(2):275-80.
Reason for exclusion: Not all patients with acute episode

Naprawa J.T., Bonsu B.K., Goodman D.G., Ranalli M.A. Serum biomarkers for identifying acute chest syndrome among patients who have sickle cell disease and present to the emergency department. Pediatrics 2005;116(3):e420-25.
Reason for exclusion: Focus on diagnosis

Noreldeen S.A., Oppenheimer C., Chapman C., Pavord S. Postpartum acute splenic sequestration in sickle cell disease. Journal of Obstetrics & Gynaecology 2008;28(4):440-41.
Reason for exclusion: Case series or case study

Norris S., Johnson C.S., Haywood L.J. Sickle cell anemia: does myocardial ischemia occur during crisis? Journal of the National Medical Association 1991;83(3):209-13.
Reason for exclusion: Descriptive prevalence/cross sectional study

Nur E., Brandjes D.P., Schnog J.J., Otten H.M., Fijnvandraat K., Schalkwijk C.G., et al. Plasma levels of advanced glycation end products are associated with haemolysis-related organ complications in sickle cell patients. British Journal of Haematology 2010;151(1):62-69.
Reason for exclusion: Not all patients with acute episode

Nur E., Mairuhu W., Biemond B.J., van Zanten A.P., Schnog J.J., Brandjes D.P., et al. Urinary markers of bone resorption, pyridinoline and deoxypyridinoline, are increased in sickle cell patients with further increments

during painful crisis. American Journal of Hematology 2010;85(11):902-04.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Oliveira C.C., Ciasca S.M., Moura-Ribeiro M.V. Stroke in patients with sickle cell disease: clinical and neurological aspects. Arquivos de Neuro-Psiquiatria 2008;66(1):30-33.
Reason for exclusion: Not all patients with acute episode

Onuaguluchi G. & Akande E.O. Severe crises with jaundice in young non-pregnant adults with sickle-cell haemoglobin-C disease. Lancet 1966;1(7440):737-39.
Reason for exclusion: Case series or case study

Pannu R., Zhang J., Andraws R., Armani A., Patel P., Mancusi-Ungaro P. Acute myocardial infarction in sickle cell disease: a systematic review. Critical Pathways in Cardiology: A Journal of Evidence-Based Medicine 2008;7(2):133-38.
Reason for exclusion: Review

Polizzotto M.N., Shortt J., Cole-Sinclair M.F. Acute splenic sequestration complicating sickle cell disease. European Journal of Haematology 2008;81(1):81.
Reason for exclusion: Case series or case study

Poncz M., Kane E., Gill F.M. Acute chest syndrome in sickle cell disease: etiology and clinical correlates. Journal of Pediatrics 1985;107(6):861-66.
Reason for exclusion: Descriptive prevalence/cross sectional study

Radel E.G., Kochen J.A., Finberg L. Hyponatremia in sickle cell disease. A renal salt-losing state. Journal of Pediatrics 1976;88(5):800-05.
Reason for exclusion: Inaccessible

Reagan M.M., DeBaun M.R., Frei-Jones M.J. Multi-modal intervention for the inpatient management of sickle cell pain significantly decreases the rate of acute chest syndrome. Pediatric Blood & Cancer 2011;56(2):262-66.

Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Roberts G.J., Haas R.A., King F.M. Emergency-room crises in sickle-cell disease. Lancet 1973;1(7818):1511.
Reason for exclusion: Editorial/letter

Savage W.J., Everett A.D., Casella J.F. Plasma glial fibrillary acidic protein levels in a child with sickle cell disease and stroke. Acta Haematologica 2011;125(3):103-06.
Reason for exclusion: Case series or case study

Scott L.K., Grier L.R., Arnold T.C., Conrad S.A. Serum procalcitonin concentration as a negative predictor of serious bacterial infection in acute sickle cell pain crisis. Medical Science Monitor 2003;9(10):CR426-31.
Reason for exclusion: Focus on diagnosis

Seeler R.A. & Shwiaki M.Z. Acute splenic sequestration crises (ASSC) in young children with sickle cell anemia. Clinical observations in 20 episodes in 14 children. Clinical Pediatrics 1972;11(12):701-04.
Reason for exclusion: Management of acute complication

Seidman C., Kirkham F., Pavlakis S. Pediatric stroke: current developments. Current Opinion in Pediatrics 2007;19(6):657-62.
Reason for exclusion: Review

Sen N., Kozanoglu I., Karatasli M., Ermis H., Boga C., Eyuboglu F.O. Pulmonary function and airway hyperresponsiveness in adults with sickle cell disease. Lung 2009;187(3):195-200.
Reason for exclusion: Not all patients with acute episode

Serafini A.N., Spoliansky G., Sfakianakis G.N., Montalvo B., Jensen W.N. Diagnostic studies in patients with sickle cell anemia and acute abdominal pain. Archives of Internal Medicine 1987;147(6):1061-62.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Silva C.M., Giovani P., Viana M.B. High reticulocyte count is an independent risk factor for cerebrovascular disease in children with sickle cell anemia. Pediatric Blood & Cancer 2011;56(1):116-21.
Reason for exclusion: Not all patients with acute episode

Sokol J.A., Baron E., Lantos G., Kazim M. Orbital compression syndrome in sickle cell disease. Ophthalmic Plastic & Reconstructive Surgery 2008;24(3):181-84.
Reason for exclusion: Case series or case study

Sprinkle R.H., Cole T., Smith S., Buchanan G.R. Acute chest syndrome in children with sickle cell disease. A retrospective analysis of 100 hospitalized cases. American Journal of Pediatric Hematology/Oncology 1986;8(2):105-10.
Reason for exclusion: Descriptive prevalence/cross sectional study

Stankovic Stojanovic K., Steichen O., Lionnet F., Bachmeyer C., Lecomte I., Avellino V., et al. Is procalcitonin a marker of invasive bacterial infection in acute sickle-cell vaso-occlusive crisis? Infection 2011;39(1):41-45.
Reason for exclusion: Focus on diagnosis

Strouse J.J., Hulbert M.L., DeBaun M.R., Jordan L.C., Casella J.F. Primary hemorrhagic stroke in children with sickle cell disease is associated with recent transfusion and use of corticosteroids. Pediatrics 2006;118(5):1916-24.
Reason for exclusion: Not all patients with acute episode

Strouse J.J., Jordan L.C., Lanzkron S., Casella J.F. The excess burden of stroke in hospitalized adults with sickle cell disease. American Journal of Hematology 2009;84(9):548-52.
Reason for exclusion: Not all patients with acute episode

Sylvester K.P., Patey R.A., Rafferty G.F., Rees D., Thein S.L., Greenough A. Airway hyperresponsiveness and acute chest syndrome in children with sickle cell anemia. Pediatric Pulmonology 2007;42(3):272-76.
Reason for exclusion: Not all patients with acute episode

Tanner M.A., Westwood M.A., Pennell D.J. Myocardial infarction following sickle cell chest syndrome. British Journal of Haematology 2006;134(1):2.
Reason for exclusion: Case series or case study

Uong E.C., Boyd J.H., DeBaun M.R. Daytime pulse oximeter measurements do not predict incidence of pain and acute chest syndrome episodes in sickle cell anemia. Journal of Pediatrics 2006;149(5):707-09.
Reason for exclusion: Not all patients with acute episode

Valman H.B. ABC of 1 to 7: Acute abdominal pain. British Medical Journal Clinical Research Ed 1981;282(6279):1858-60.
Reason for exclusion: Case series or case study

van Beers E.J., van Tuijn C.F., Mac Gillavry M.R., van der Giessen A., Schnog J.J., Biemond B.J., CURAMA study group. Sickle cell disease-related organ damage occurs irrespective of pain rate: implications for clinical practice. Haematologica 2008;93(5):757-60.
Reason for exclusion: Not all patients with acute episode

Viana M.B., Rezende P.V., Murao M., Janurio J.N., Chaves A.C.L., Ribeiro.A.C.F. Acute splenic sequestration in a cohort of children derived from the Newborn Screening Program for sickle cell anemia in Minas Gerais, Brazil. American Journal of Hematology 2009;Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Co(var.pagings)
Reason for exclusion: Not all patients with acute episode

Vichinsky E.P., Styles L.A., Colangelo L.H., Wright E.C., Castro O., Nickerson B. Acute chest syndrome in sickle cell disease: clinical presentation and course. Cooperative Study of Sickle Cell Disease. Blood 1997;89(5):1787-92.
Reason for exclusion: Not all patients with acute episode

Wajima T. Nitroblue tetrazolium test in patients with sickle-cell anemia. American Journal of Clinical Pathology 1975;64(5):608-12.
Reason for exclusion: Focus on diagnosis

Wells B.L., Vizioli T.L., Counselman F.L. The reticulocyte count: is it needed for evaluating typical sickle cell crisis presenting to the ED? American Journal of Emergency Medicine 2002;20(1):69-70.
Reason for exclusion: Not focused on risk factors for acute complication or not clinical/laboratory risk factor

Wilson W.A. & Alleyne G.A. Renal function during painful sickle cell crisis. West Indian Medical Journal 1975;24(2):84-89.
Reason for exclusion: Not acute complication/no diagnosis of acute complication/no specific acute complication

Winter S.S., Kinney T.R., O'Branski E.E., Ware R.E. Evaluation and management of acute neurologic symptoms in children with sickle cell disease. International Journal of Pediatric Hematology/Oncology 1997;4(4):339-46.
Reason for exclusion: Not all patients with acute episode

Wong A.L., Sakamoto K.M., Johnson E.E. Differentiating osteomyelitis from bone infarction in sickle cell disease. Pediatric Emergency Care 1964;17(1):60-63.
Reason for exclusion: Inaccessible

WRIGHT C.S. & GARDNER E Jr. A study of the role of acute infections in precipitating crises in chronic hemolytic states. Annals of Internal Medicine 1960;52:530-37.
Reason for exclusion: Not human study

Yates A.M., Hankins J.S., Mortier N.A., Aygun B., Ware R.E. Simultaneous acute splenic sequestration and transient aplastic crisis in children with sickle cell disease. Pediatric Blood & Cancer 2009;53(3):479-81.
Reason for exclusion: Case series or case study

No authors listed. Acute complications of sickle cell disease in children. Drug & Therapeutics Bulletin 2001;39(5):33-37.
Reason for exclusion: Review

No authors listed. Multiorgan failure during sickle cell pain. Emergency Medicine (00136654) 1995;27(6):71-74.
Reason for exclusion: Review

Full list of excluded papers for review question 4: Settings and skills for managing an acute painful episode

1989. Sickle cell disease and the non-specialist. Drug and Therapeutics Bulletin, 27, (3) 9-12

Ref ID: 7167

Notes: UI - 1989046825

EXCLUDE-NARRATIVE REVIEW/OPINION PIECE

2003. A multipronged approach needed for successful management of sickle cell anaemia. Drugs & Therapy Perspectives, 19, (5) 10-14

Ref ID: 8324

EXCLUDE-NARRATIVE OVERVIEW OF SICKLE CELL DISEASE

Adewoye, A.H., Nolan, V., McMahon, L., Ma, Q., & Steinberg, M.H. 2007. Effectiveness of a dedicated day hospital for management of acute sickle cell pain. Haematologica, 92, (6) 854-855

Ref ID: 637

EXCLUDE-LETTER

Artz, N., Whelan, C., & Feehan, S. 2010. Caring for the adult with sickle cell disease: results of a multidisciplinary pilot program. Journal of the National Medical Association, 102, (11) 1009-1016

Ref ID: 60

EXCLUDE-NOT FOCUSED ON ACUTE SICKLE CELL PAINFUL EPISODES

Ballas, S.K., Axelrod, D.J., Riggio, J.M., & Riddick-Burden, G. 2009. Serum levels of opioids in patients with sickle cell disease treated in the day unit. Pain Medicine, Conference: 25th Annual Meeting of the American Academy of Pain Medicine, AAPM Honolulu, HI United States. Conference Start: 20090127 Conference End: 20090131. Conference Publication: (var.pagings) 243-244

Ref ID: 4373

EXCLUDE-CONFERENCE ABSTRACT

Beach, M.C., Brown, R., Hughes, M., Haywood, C., Lanzkron, S., Massa, M., & Ratanawongsa, N. 2010. Improving clinician attitudes toward patients with sickle cell disease: The impact of a film intervention. Journal of General Internal Medicine, Conference: 33rd Annual Meeting of the Society of General Internal Medicine Minneapolis, MN United States. Conference Start: 20100428 Conference End: 20100501. Conference Publication: (var.pagings) S307
Ref ID: 3756

EXCLUDE-CONFERENCE ABSTRACT

Bellevue, R., Guillaume, E., Sundaram, R., Duroseau, H., D'Agustine, J., Singh, S., Blackwood, M., Souffrant, H., Webb, C., Boliscar, R., & Escobar, L. 2009. A model of coordinated comprehensive care for pediatrics and adult patients with sickle cell disease in Brooklyn, New York. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E160
Ref ID: 4152
EXCLUDE-ABSTRACT ONLY

Benjamin, L. 2008. Pain management in sickle cell disease: palliative care begins at birth? Hematology 466-474
Ref ID: 380
EXCLUDE-OVERVIEW OF PAIN MANAGEMENT

Bojanowski, C. 1989. Use of protocols for ED patients with sickle cell anemia. JEN: Journal of Emergency Nursing, 15, (2) 83-88
Ref ID: 8560
EXCLUDE-DESCRIPTION OF MANAGEMENT PROTOCOL

Brandow, A.M., Weisman, S.J., & Panepinto, J.A. 2011. The impact of a multidisciplinary pain management model on sickle cell disease pain

hospitalizations. Pediatric Blood & Cancer, 56, (5) 789-793
Ref ID: 3488
EXCLUDE-SET IN PAIN CLINIC (NOT FOCUSED ON ACUTE PAIN)

Brownlee, J. 2009. Patient education and nurse's education can improve compliance in Sickle Cell patients. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E132
Ref ID: 4160

EXCLUDE-CONFERENCE ABSTRACT

Burnette, M. 2009. Providing culturally competent sickle cell care. Minority Nurse 28-32
Ref ID: 8048

EXCLUDE-OPINION ARTICLE

Carvalho, E.M.M., Queiroz, A.M.M., Moraes, M.H.P., Lobo, C.L.C., & Queiroz, A.P.A. 2009. Disclosure Project for awareness of pain in healthcare treatment. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E43
Ref ID: 4194
EXCLUDE-CONFERENCE ABSTRACT

Co, J.P., Johnson, K.B., Duggan, A.K., Casella, J.F., & Wilson, M. 2003. Does a clinical pathway improve the quality of care for sickle cell anemia? Joint Commission Journal on Quality & Safety, 29, (4) 181-190
Ref ID: 1225

EXCLUDE-FOCUS ON CLINICAL PATHWAY WITH NO FOCUS ON ORGANISATION OF CARE OR SKILLS/KNOWLEDGE OF HEALTHCARE PROFESSIONALS

Cooper, G.S., Armitage, K.B., Ashar, B., Costantini, O., Creighton, F.A., Raiz, P., Wong, R.C., & Carlson, M.D. 2000. Design and implementation of an inpatient disease management program. American Journal of Managed Care, 6, (7) 793-801
Ref ID: 1553
EXCLUDE-NOT FOCUSED ON SICKLE CELL DISEASE AND NO FOCUS ON ORGANISATION OF CARE OR SKILLS/ KNOWLEDGE OF HEALTHCARE PROFESSIONALS

Crockett, R.K. 1989. Pain management in the pediatric emergency department. International Pediatrics, 4, (1) 14-18
Ref ID: 7147
EXCLUDE-NARRATIVE REVIEW OF PAIN IN SICKLE CELL DISEASE

Day, J. 1998. Crisis management... a nurse-led programme of pain management for patients with sickle cell crisis... NT/3M National Nursing Awards. Nursing Times, 94, (1) 28-30
Ref ID: 8482
EXCLUDE-OPINION PIECE

De, D. 2005. Pain management. Sickle cell anaemia 2: management approaches of painful episodes. British Journal of Nursing (BJN), 14, (9) 484-490
Ref ID: 8227
EXCLUDE-NARRATIVE REVIEW

De, D. 2008. Acute nursing care and management of patients with sickle cell. [Review] [21 refs]. British Journal of Nursing, 17, (13) 818-823
Ref ID: 403
EXCLUDE-NARRATIVE REVIEW/OPINION PIECE

Dohrenwend, A. & Sehgal, R. 2005. Lost between the cracks: pain patients denied inpatient treatment for illicit drug addiction. Psychosomatic Medicine, 67, (4) 677-678
Ref ID: 925
EXCLUDE-LETTER

Elander, J., Marczewska, M., Amos, R., Thomas, A., & Tangayi, S. 2006. Factors affecting hospital staff judgments about sickle cell disease pain. Journal of Behavioral Medicine, 29, (2) 203-214
Ref ID: 843
EXCLUDE-FOCUS ON JUDGEMENTS OF HEALTHCARE PROFESSIONALS

Forbes, K., Forbes, B., & Lee, A. 1998. "Sickle cell-related pain: Perceptions of medical practitioners": Comment. Journal of Pain and Symptom Management, 15, (6) 333-334
Ref ID: 8777
EXCLUDE-LETTER

Freed, J. & Ender, K.L. 2009. Acute management of vaso-occlusive pain in pediatric sickle cell disease. Pediatric Blood and Cancer, Conference: American Society of Pediatric Hematology/Oncology 22nd Annual Meeting San Diego, CA United States. Conference Start: 20090422 Conference End: 20090425. Conference Publication: (var.pagings) 727
Ref ID: 4220

EXCLUDE-CONFERENCE ABSTRACT

Haywood, C. & Beach, M.C. 2009. Previous interpersonal experiences with health care and sickle cell patient trust. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E25

Ref ID: 4204
EXCLUDE-ABSTRACT ONLY

Haywood, C., Jr., Lanzkron, S., Hughes, M.T., Brown, R., Massa, M., Ratanawongsa, N., & Beach, M.C. 2011. A video-intervention to improve clinician attitudes toward patients with sickle cell disease: the results of a randomized experiment. Journal of General Internal Medicine, 26, (5) 518-523
Ref ID: 3484
EXCLUDE-EFFECTIVENESS OF EDUCATIONAL INTERVENTION

Hei, D.L. & Lottenberg, R. 2001. Helping patients through a sickle cell crisis. Patient Care, 35, (24) 29-36
Ref ID: 8375
EXCLUDE-LITERATURE REVIEW

Houser, B., Plawecki, H.M., Carr, J., Smith, M.A., & Plawecki, J.A. 1992. A holistic approach to vaso-occlusive pain crisis in children with sickle cell disease. Journal of Holistic Nursing, 10, (1) 62-75
Ref ID: 2299
EXCLUDE-NARRATIVE REVIEW OF PAIN IN SICKLE CELL DISEASE

Imbach, P. 2008. Day hospital versus inpatient management: An economic initiative of a pediatric center, examplified on uncomplicated vaso-occlusive crises of children with sickle cell disease. Pediatric Blood & Cancer, 51, (3) 317
Ref ID: 431
EXCLUDE-COMMENT

Jayaram, A., Nagel, R.W., & Jasty, R. 2010. Impact of clinical pathway on quality of care in sickle cell patients. Journal of Pediatric Hematology/Oncology, 32, (7) 537-539
Ref ID: 86
EXCLUDE-CLINICAL PATHWAY NOT FOCUSED ON ORGANISATION OF CARE OR COMPETENCIES OF HEALTHCARE PROFESSIONALS PROVIDING CARE

Khattab, A.D., Rawlings, B., & Ali, I.S. 2006. Sickle cell disease. Care of patients with haemoglobin abnormalities: nursing management... second of two articles. British Journal of Nursing (BJN), 15, (19) 1057-1063
Ref ID: 8170
EXCLUDE-NARRATIVE REVIEW

Labbe, E., Herbert, D., & Haynes, J. 2005. Physicians' attitude and practices in sickle cell disease pain management.[Erratum appears in J Palliat Care. 2006 Spring;22(1):64]. Journal of Palliative Care, 21, (4) 246-251
Ref ID: 869
EXCLUDE-FOCUS ON PERCEPTIONS/ATTITUDES OF HEALTHCARE PROFESSIONALS PROVIDING CARE

Larsen, L.S., Neverett, S.G., & Larsen, R.F. 2001. Clinical nurse specialist as facilitator of interdisciplinary collaborative program for adult sickle cell population. [Review] [22 refs]. Clinical Nurse Specialist, 15, (1) 15-22
Ref ID: 1393
EXCLUDE-DESCRIPTION OF CLINICAL PATHWAY

Lewing, K., Britton, K., Debaun, M., & Woods, G. 2011. The impact of parenteral narcotic choice in the development of acute chest syndrome in sickle cell disease. Journal of Pediatric Hematology/Oncology, 33, (4) 255-260
Ref ID: 3478
EXCLUDE-TO CONSIDER FOR RQ3

Lombard, M.R.P., Xie, Y., & Niihara, Y. 2001. Disease-specific management in a primary care setting: case studies of successful outpatient management of sickle cell painful crises. Medicine of the Americas, 2, (1) 70-75
Ref ID: 8409
EXCLUDE-UNAVAILABLE

Lorenzi, E.A. 1993. The effects of comprehensive guidelines for the care of sickle-cell patients in crisis on the nurses' knowledge base and job satisfaction for care given. Journal of Advanced Nursing, 18, (12) 1923-1930
Ref ID: 2198

EXCLUDE-FOCUS ON IMPACT OF EDUCATIONAL INTERVENTION ON KNOWLEDGE WITH NO FOCUS ON ORGANISATION OF CARE

McGreal, S., Ahearne, M., & Chapman, C. 2009. Patient satisfaction in sickle cell disease. British Journal of Haematology, Conference: 49th Annual Scientific Meeting of the British Society for Haematology Brighton United Kingdom. Conference Start: 20090427 Conference End: 20090429. Conference Publication: (var.pagings) 25
Ref ID: 4213
EXCLUDE-POSTER ABSTRACT

Morris, K. 1999. Addressing the crisis of care for sickle-cell disease. Lancet, 353, (9163) 1504
Ref ID: 1675
EXCLUDE-OPINION PIECE

Neumayr, L., Pringle, S., Giles, S., Quirolo, K.C., Paulukonis, S., Vichinsky, E.P., & Treadwell, M.J. 2010. Chart card: Feasibility of a tool for improving emergency department care in sickle cell disease. Journal of the National Medical Association, 102, (11) 1017-1023
Ref ID: 3807

EXCLUDE- NO FOCUS ON ORGANISATION OF CARE

Odesina, V.O. 10 A.D. Sickle cell pain management in the emergency department: A two phase quality improvement project. Dissertation Abstracts International: Section B: The Sciences and Engineering, 71, (4-B) 2315
Ref ID: 8585
EXCLUDE-DISSERTATION ABSTRACT ONLY

Pack-Mabien, A., Labbe, E., Herbert, D., & Haynes, J., Jr. 2001. Nurses' attitudes and practices in sickle cell pain management. Applied Nursing Research, 14, (4) 187-192
Ref ID: 1421
EXCLUDE-FOCUS ON FACTORS AFFECTING NURSES ATTITUDES

Paulukonis, S., Neumayr, L., Treadwell, M., Quirolo, K., Pringle, S., Giles, S., Harrison, R., Orsini, F., Hagar, W., Hale, L., Rutherford, M., Hawk, W., Schrager, S., Lubin, B., & Vichinsky, E. 2009. Chart card: A tool for improving emergency room care in sickle cell disease. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E157-E158
Ref ID: 4153
EXCLUDE-ABSTRACT ONLY

Pervaiz, S.M., McConalogue, D., Chacon, A., Poulton, J., & Mehta, P. 2009. Survey of patient's perception of a haemoglobinopathy service in the hospital and in the community: Is there a need for the role of a clinical nurse specialist? British Journal of Haematology, Conference: 49th Annual Scientific Meeting of the British Society for Haematology Brighton United Kingdom. Conference Start: 20090427 Conference End: 20090429. Conference Publication: (var.pagings) 70
Ref ID: 4211
EXCLUDE-POSTER ABSTRACT

Platt, A., Eckman, J.R., Beasley, J., & Miller, G. 2002. Treating sickle cell pain: an update from the Georgia Comprehensive Sickle Cell Center. JEN: Journal of Emergency Nursing, 28, (4) 297-310
Ref ID: 8351
EXCLUDE-OPINION PIECE FROM CLINICAL EXPERIENCE

Platt, A.F., Jr. & Eckman, J.R. 1989. The multidisciplinary management of pain in patients with sickle cell syndrome. Journal of the American Academy of Physician Assistants, 2, (2) 104-114
Ref ID: 8561
EXCLUDE-DESCRIPTION OF PAIN MANAGEMENT

Preboth, M. 2000. Practice guidelines. Management of pain in sickle cell disease. American Family Physician, 61, (5) 1544-1547
Ref ID: 8432

EXCLUDE-GUIDELINE

Queiroz, A.P.A., Queiroz, A.M.M., Neves, A.F., Lobo, C.L.C., & Carvalho, E.M. 2009. Development and evaluation of a tool to improve the quality of service provided to Sickle cell disease patients at HEMORIO. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E42
Ref ID: 4195
EXCLUDE-ABSTRACT ONLY

Rausch, M. & Pollard, D. 1998. Management of the patient with sickle cell disease. Journal of Intravenous Nursing, 21, (1) 27-40
Ref ID: 6464
EXCLUDE-NARRATIVE REVIEW OF SICKLE CELL DISEASE

Schrag, D., Xu, F., Hanger, M., Elkin, E., Bickell, N.A., & Bach, P.B. 2006. Fragmentation of care for frequently hospitalized urban residents. Medical Care, 44, (6) 560-568
Ref ID: 8186
EXCLUDE-NOT FOCUSED ON ORGANISATION OF CARE OR COMPETENCIES OF HEALTHCARE PROFESSIONALS

Shaiova, L. & Wallenstein, D. 2004. Outpatient management of sickle cell pain with chronic opioid pharmacotherapy. Journal of the National Medical Association, 96, (7) 984-986
Ref ID: 1065
EXCLUDE-CASE SERIES

Shapiro, B.S., Benjamin, L.J., Payne, R., & Heidrich, G. 1997. Sickle cell-related pain: perceptions of medical practitioners. Journal of Pain & Symptom Management, 14, (3) 168-174
Ref ID: 1873
EXCLUDE-FOCUS ON PERCEPTIONS/ATTITUDES OF HEALTHCARE PROFESSIONALS PROVIDING CARE

Smith-Wynter, L. & van, O. 1999. Research study. The feasibility of nursing patients with sickle cell crisis at home. British Journal of Community Nursing, 4, (10) 531-538
Ref ID: 8446
EXCLUDE-PAIN MANAGEMENT IN COMMUNITY SETTINGS

Solomon, L.R. 2008. Treatment and prevention of pain due to vaso-occlusive crises in adults with sickle cell disease: an educational void. Blood, 111, (3) 997-1003
Ref ID: 513
EXCLUDE-PERSPECTIVE FOCUSING ON PAIN MANAGEMENT INFORMTAION IN MEDICAL TEXT BOOKS

Swinburne, C. 2002. Crisis management... sickle-cell anaemia. Nursing Times, 98, (15) 28-30
Ref ID: 8365
EXCLUDE-OPINION ARTICLE

Tanabe, P., Myers, R., Zosel, A., Brice, J., Ansari, A.H., Evans, J., Martinovich, Z., Todd, K.H., & Paice, J.A. 2007. Emergency department management of acute pain episodes in sickle cell disease. Academic Emergency Medicine, 14, (5) 419-425
Ref ID: 650
EXCLUDE-PROVIDES OVERVIEW OF CLINICAL PRACTICE (NO FOCUS ON ORGANISATION OF CARE OR COMPETENCIES)

Tanabe, P., Hafner, J.W., Courtney, D.M., Martinovich, Z., Zvirbulis, E., & Artz, N. 2009. The emergency department pain experience for adults With sickle cell disease. Annals of Emergency Medicine, Conference: American

College of Emergency Physicians, ACEP 2009 Research Forum Boston, MA United States. Conference Start: 20091005 Conference End: 20091006. Conference Publication: (var.pagings) S14
Ref ID: 4246
EXCLUDE-CONFERENCE ABSTRACT

Tanabe, P., Lyons, J.S., Reddin, C.J., Thornton, V.L., Wun, T., & Todd, K.H. 2009. A qualitative study assessing the information needed to manage adults in the emergency department with sickle cell disease. Annals of Emergency Medicine, Conference: American College of Emergency Physicians, ACEP 2009 Research Forum Boston, MA United States. Conference Start: 20091005 Conference End: 20091006. Conference Publication: (var.pagings) S14
Ref ID: 4247
EXCLUDE-CONFERENCE ABSTRACT

Tanabe, P., Wun, T., Thornton, V., Todd, K., & Lyons, J.S. 2009. Development of a decision support tool to guide management of adults with sickle cell disease: The emergency department sickle cell assessment of strengths and needs (ED-SCANS). Blood, Conference: 51st Annual Meeting of the American Society of Hematology, ASH New Orleans, LA United States. Conference Start: 20091205 Conference End: 20091208. Conference Publication: (var.pagings)
Ref ID: 4320
EXCLUDE-POSTER ABSTRACT

Tanabe, P., Reddin, C., Thornton, V.L., Todd, K.H., Wun, T., & Lyons, J.S. 2010. Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS), a focus group and decision support tool development project. Academic Emergency Medicine, 17, (8) 848-858
Ref ID: 81

EXCLUDE-FOCUS ON INITIAL ASSESSMENT

Tanabe, P., Artz, N., Mark Court, Martinovich, Z., Weiss, K.B., Zvirbulis, E., & Hafner, J.W. 2010. Adult emergency department patients with sickle cell pain

crisis: a learning collaborative model to improve analgesic management. Academic Emergency Medicine, 17, (4) 399-407
Ref ID: 150
EXCLUDE-DESCRIPTIVE STUDY WITH NO COMPARISONS AND LIMITED DETAILS OF INTERVENTION

Thomas, V.N. & Westerdale, N. 1996. Managing sickle cell disease: the hospital-community interface. British Journal of Community Health Nursing, 1, (8) 466-472
Ref ID: 8501
EXCLUDE-OPINION PIECE

Valente, S., Alexander, J., Blount, M., Fair, J., Goldsmith, C., & Williams, L. 2010. Sickle cell disease in emergency department: education for emergency nurses. JOCEPS: The Journal of Chi Eta Phi Sorority, 54, (1) 11-15
Ref ID: 8005

EXCLUDE-UNAVAILABLE

Vichinsky, E.P., Johnson, R., & Lubin, B.H. 1982. Multidisciplinary approach to pain management in sickle cell disease. American Journal of Pediatric Hematology/Oncology, 4, (3) 328-333
Ref ID: 3019
EXCLUDE-NOT FOCUSED ON ORGANISATION OF CARE OR COMPETENCIES OF HEALTHCARE PROFESSIONALS

Waldrop, R.D. & Mandry, C. 1995. Health professional perceptions of opioid dependence among patients with pain. American Journal of Emergency Medicine, 13, (5) 529-531
Ref ID: 2075
EXCLUDE-FOCUS ON THE PERCEPTIONS OF HEALTHCARE PROFESSIONALS

Ware, M.A. 1998. Fast track admission for children with sickle cell crises. Jamaican sickle cell clinics offer an alternative to admission. BMJ, 316, (7135) 934

Ref ID: 1810
EXCLUDE-LETTER

Ware, M.A., Hambleton, I., Ochaya, I., & Serjeant, G.R. 1999. Day-care management of sickle cell painful crisis in Jamaica: a model applicable elsewhere? British Journal of Haematology, 104, (1) 93-96
Ref ID: 1698
EXCLUDE-DESCRIPTIVE STUDY OF DAY CARE MANAGEMENT

Webb, T., Roth, G., Wilson, S., & Lavender, A. 2009. Use of an internet-based, care coordination tool in patient-centered, collaborative care. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E192
Ref ID: 4134
EXCLUDE-ABSTRACT ONLY

Wilsey, B., Fishman, S., Rose, J.S., & Papazian, J. 2004. Pain management in the ED. American Journal of Emergency Medicine, 22, (1) 51-58
Ref ID: 8296
EXCLUDE-NARRATIVE REVIEW

Wood, D.A. 2003. RNs help take the edge off sickle cell pain. Nursing Spectrum -- Florida Edition, 13, (16) 10-11
Ref ID: 8315
EXCLUDE-OVERVIEW OF PAIN MANAGEMENT

Yale, S.H., Nagib, N., & Guthrie, T. 2000. Approach to the vaso-occlusive crisis in adults with sickle cell disease. American Family Physician, 61, (5) 1349-1364
Ref ID: 6232
EXCLUDE-NARRATIVE REVIEW

Zempsky, W.T., Loiselle, K.A., McKay, K., Lee, B.H., Hagstrom, J.N., & Schechter, N.L. 2010. Do children with sickle cell disease receive disparate care for pain in the emergency department? Journal of Emergency Medicine, 39, (5) 691-695

Ref ID: 47

EXCLUDE-NOT FOCUSED ON ORGANISATION OF CARE OR COMPETENECIES OF HEALTHCARE PROFESSIONALS

List of excluded studies for review question 5-Information and support needs for patients and their carers during an acute painful episode

008. Summaries for patients. Pain and health care visits in patients with sickle cell disease. Annals of Internal Medicine, 148, (2) I36
Ref ID: 525
EXCLUDE: PAIN AT HOME

2010. Study reveals high rates of rehospitalizations and emergency pain treatment for sickle cell disease. AHRQ Research Activities (358) 16-18
Ref ID: 7977
EXCLUDE: DOES NOT CONSIDER PATIENT EXPERIENCES

Anderson, L.P. 1982. The relationship between perception of pain, cognitive behavioral variables and coping strategies in chronic pain patients. Dissertation Abstracts International, 42, (11-B) 4566
Ref ID: 8845
EXCLUDE: ABSTRACT ONLY

Anionwu, E. & Bennett, L. 2008. The sickle cell crisis. Interview by Stephanie Northen. Nursing Standard, 23, (8) 22-23
Ref ID: 395
EXCLUDE: DESCRIPTIVE OVERVIEW

Ballas, S.K., Park, C.H., & Jacobs, S.R. 1995. The spectrum of painful episodes in adult sickle cell disease. Pain Digest, 5, (2) 73-89
EXCLUDE: REVIEW ARTICLE

Barakat, L.P., Schwartz, L.A., Salamon, K.S., & Radcliffe, J. 2010. A family-based randomized controlled trial of pain intervention for adolescents with sickle cell disease. Journal of Pediatric Hematology/Oncology, 32, (7) 540-547
Ref ID: 87
EXCLUDE: HOME PAIN MANAGEMENT

Brandow, A.M., Brousseau, D.C., & Panepinto, J.A. 2009. Post-discharge pain, functional limitations and impact on caregivers of children with sickle cell disease treated for painful events. British Journal of Haematology, 144, (5)

782-788
Ref ID: 195
EXCLUDE: HOME PAIN MANAGEMENT

Britto, M.T., DeVellis, R.F., Hornung, R.W., DeFriese, G.H., Atherton, H.D., & Slap, G.B. 2004. Health care preferences and priorities of adolescents with chronic illnesses. Pediatrics, 114, (5) 1272-1280
Ref ID: 1024
EXCLUDE: OTHER CONDITIONS COVERED AS WELL AS SICKLE CELL DISEASE

Brownlee, J. 2009. Patient education and nurses education can improve compliance in Sickle Cell patients. American Journal of Hematology, Conference: 3rd Annual Sickle Cell Disease Research and Educational Symposium and Grant Writing Institute and Annual National Sickle Cell Disease Scientific Meeting Fort Lauderdale, FL United States. Conference Start: 20090215 Conference End: 20090220. Conference Publication: (var.pagings) E132
Ref ID: 4160
EXCLUDE: ABSTRACT ONLY

Butler, D.J. & Beltran, L.R. 1993. Functions of an adult sickle cell group: education, task orientation, and support. Health & Social Work, 18, (1) 49-56
Ref ID: 2281
EXCLUDE: NOT ABOUT PATIENT EXPERIENCES

Campbell, A.D., Ross, P.T., Kumagai, A.K., Christner, J.G., & Lypson, M.L. 2010. Coming of age with sickle cell disease and the role of patient as teacher. Journal of the National Medical Association, 102, (11) 1073-1078
Ref ID: 57
EXCLUDE: NOT ABOUT INPATIENT EXPERIENCES

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