SCD patients’ experiences of hospital pain management
(presentation 1 of a series of 3)
What this presentation is about

- Pain in SCD
- When hospital pain management goes wrong
- Respect and trust in healthcare
- Patients’ perspectives
- Hospital staff perspectives
- Potential explanations
Why sickle cell disease is painful

Sickle haemoglobin (HbS) differs from normal haemoglobin (HbA) in just one amino acid out of 574 (Valine for glutamic acid at position 6 in the beta chain of the globin portion)

HbS molecules tend to stick together when oxygen is released

This deforms shape of red blood cells and reduces their flexibility

Circulation in small blood vessels is disrupted by sickled red blood cells (‘vascular occlusion’)

This causes ‘ischaemic’ pain and tissue damage
SCD pain

- Episodic, recurrent, very severe
- Fatigue, cold, damp, stress are risk factors
- Demography
  - Most painful episodes treated at home
  - The most severe treated in hospital
- Analgesics include some of the strongest opiate painkillers like morphine
When hospital pain management goes wrong

‘Concern-raising behaviours’:

- Staff-patient disputes
- Accusations/suspicions of painkiller abuse
- Using non-prescribed painkillers
- Tampering with analgesic delivery systems
- Self-discharge from hospital
Respect and trust in healthcare

Healthcare provider’s respect

- Respectful attitude to patient
- Respectful behaviour towards patient

Patient’s trust

- Respect is experienced
- Trust develops
Proportion of patients reporting concern-raising behaviours (CRBs)

<table>
<thead>
<tr>
<th>CRB</th>
<th>Baltimore USA</th>
<th>London UK</th>
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<tbody>
<tr>
<td>Disputes with staff</td>
<td>66%</td>
<td>39%</td>
</tr>
<tr>
<td>Suspected/accused of painkiller abuse</td>
<td>31%</td>
<td>20%</td>
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<tr>
<td>Used non-prescribed painkillers</td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>Tampered with analgesic delivery system</td>
<td>32%</td>
<td>4%</td>
</tr>
<tr>
<td>Self-discharged from hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least one CRB</td>
<td>49%</td>
<td>14%</td>
</tr>
<tr>
<td>At least one CRB</td>
<td>79%</td>
<td>59%</td>
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</tbody>
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(Elander et al., in press)
Patients experiences of hospital pain management

“They don’t believe you, they’re biased against sickle cell people”

“I am just afraid to come into hospital because of the (attitudes of) the nurses”

“They treat us like liars when we are in pain”

“They’re very slow to get painkillers, they don’t appreciate the pain you are in”

“Sometimes if they don’t understand what triggers the pain then they think that you’re lying”

(Harris et al., 1998)
Wider evidence about patients’ experiences

Summary of 3 studies in the US and 5 in the UK
Consistent major themes in patients descriptions:

1) Stigmatization as “drug addicted”
2) Mistrust from healthcare providers
3) Patients not encouraged/allowed to participate in care process
4) Perceived lack of sympathy/caring from providers

(Alleyne and Thomas, 1994; Booker et al., 2006; Butler and Beltran, 1993; Harris et al., 1998; Maxwell et al., 1999; Shelley et al., 1994; Strickland et al., 2001; Thomas and Taylor, 2002; see Elander et al., in press, for a review)
SCD patients’ experiences compared with those of patients generally

- Not involved enough in decisions
- Not always treated with respect
- Not enough done to control pain
- Hard to find help when needed

(Lattimer al., 2010)
Hospital staff perceptions of SCD patients

Hospital health care providers made ratings about individual patients with SCD pain:

“In your opinion, how likely is this patient to …”

- Over-report their discomfort?
- Fail to comply with medical advice?
- Abuse drugs, including alcohol?
- Try to manipulate you or other providers?

(Ratanawongsa et al., 2009)
Hospital staff beliefs about SCD patients’ addiction to pain medication

- 50% believed over 20% addicted
- 20% believed over 50% addicted
- Doctors in emergency departments more likely to believe patients were addicted (Shapiro et al., 1997)

- Estimates higher for SCD patients than other patients with pain (Waldrop and Mandry, 1995)
What is different about SCD, and SCD pain?

(Compared with other cases where powerful painkillers are used in hospital – eg cancer, terminal pain, post-operative pain, fracture/injury) Pain in SCD involves recurrent episodes of acute pain

- No objective signs of pain
- Patients are healthy between episodes
- Patients experienced in coping and managing pain
- SCD patients all members of ethnic minorities
Minority ethnic patients’ experiences of respect

- Minority ethnic patients rated their doctors more negatively than white patients did (Cooper-Patrick et al., 1999; Johnson et al., 2004b)

- Doctors rated African American patients more negatively than white patients (Van Ryn and Burke, 2000)

- Doctors observed to treat minority ethnic patients more negatively than white patients (Johnson et al., 2004a; Oliver et al., 2001)
Pain management for ethnic minority patients

- Fracture pain in hospital emergency departments (Todd et al., 1993)
- Post-operative pain (Ng et al., 1996)
- Occupational back pain (Tait et al., 2004)

(For reviews of ethnic differences in quality of pain management, see Todd et al., 2000; Green et al., 2003)
Why do SCD patients have such negative experiences?

- Racism and discrimination
- Providers’ beliefs and attitudes
- Respect and trust
- Providers’ ignorance about SCD and sickling pain
- Providers’ perceptions and beliefs about painkiller addiction
- Providers’ perceptions of patient behaviours
Conclusions/summary

- Patients’ negative experiences of hospital pain management
- Patient experiences related to respect and trust
- Patient experiences reflect wider ethnic inequalities in healthcare delivery
- ‘Concern-raising behaviours’ are an index of when pain management has gone wrong
- SCD patients perceived negatively by hospital staff
- More research needed on causes and possible interventions
References 1


Butler, D.J. and Beltran, L.R., 1993. Functions of an adult sickle cell group: education, task orientation, and support. Health and social work, 18 (1), 49-56.


References 3


