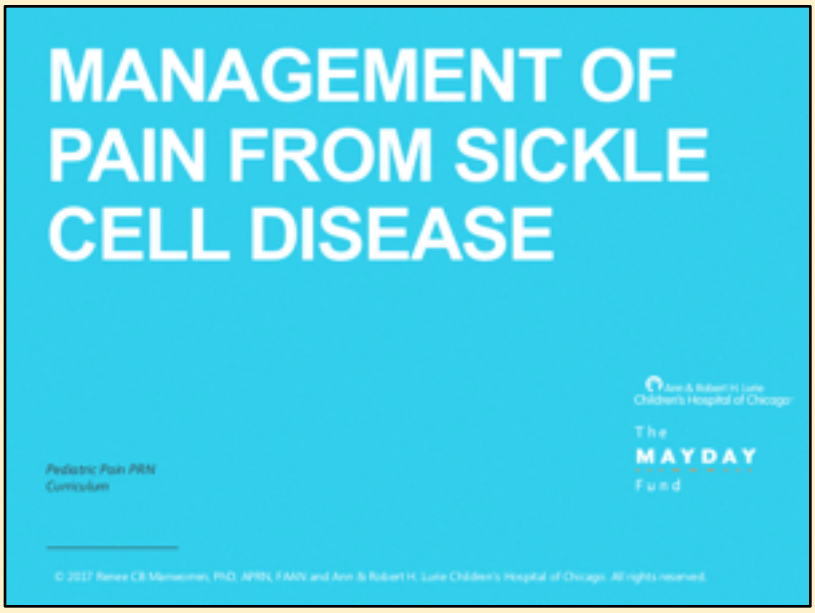
PRN Program: SCD



Materials: Flip chart or whiteboard and Markers

Room Setup: In tables of 4 or 6-8 depending on number of participants

- Display slide as participants walk in
- This session is **45 minutes**

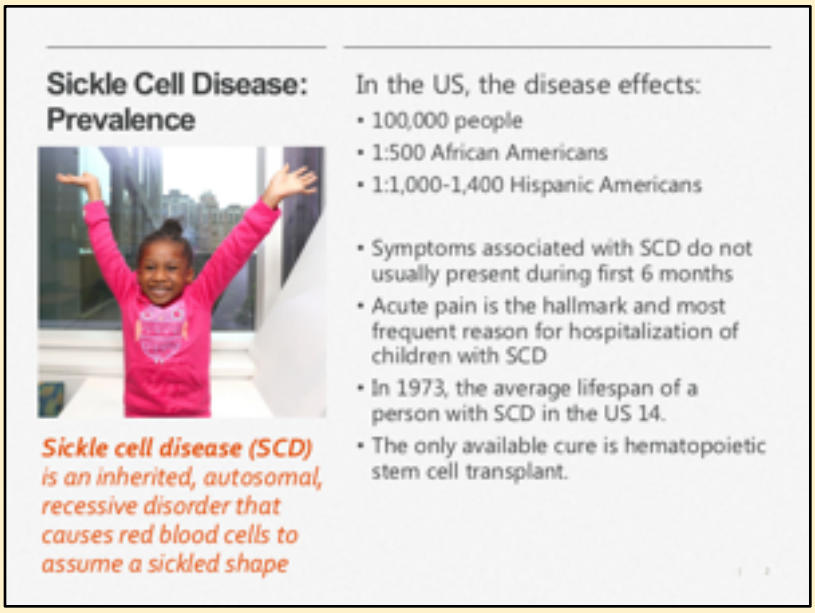
Welcome and Introductions: *Introduce facilitator if necessary*

READ:

The learning objectives for this content are to:

- Apply a multimodal approach to care for children experiencing pain from Sickle Cell Disease
- Describe age-specific pain assessment practices, diagnostic tools, and treatment strategies for pain related to Sickle Cell Disease
- Involve the patient, family and interdisciplinary care team in the management of pain from Sickle Cell Disease

PRN Program: SCD



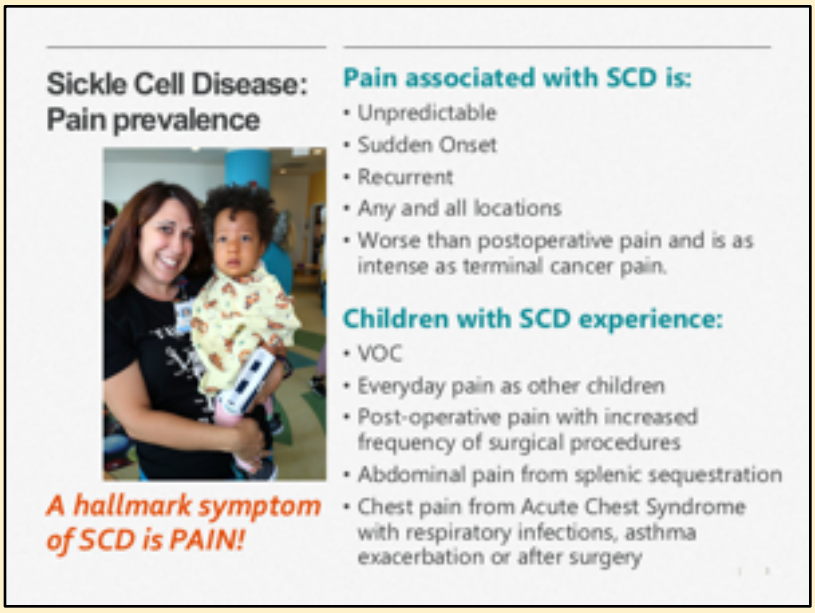
READ:

Pain experience and life expectancy is variable:

- 5-10% asymptomatic
- 10-20% seriously affected
- Tremendous resilience, strength, and courage required on the part of patients and families to secure appropriate pain management despite racial, ethnic, disease and healthcare bias
- Median life-expectancy is now in the range of 40-50 years, but likely normal for many individuals.

Unfortunately, increased frequency and severity of pain episodes are associated with early mortality.

PRN Program: SCD



READ:

A hallmark symptom of SCD is pain

Pain associated with SCD is:

- Unpredictable
- Of Sudden Onset
- Recurrent

and

- Worse than postoperative pain.

PRN Program: SCD

READ: Christopher is a 15 year old with SCD-SS who arrives in the ED accompanied by his mom. She has to go to work and can not stay. Christopher looks younger than his age. He is glassy-eyed with yellow tinged sclera and dark circles under his eyes.

ASK: What are your first impressions?

Select participants willing to share their answers to each question.
[Limit discussion to 2 minutes/question, 5 minutes total]

Potential answer:

- *Based on the dark circles under his eyes and the prevalence of sleep disturbances among individuals with SCD, he has probably not slept.*

ASK: What pain assessment strategies would you would use?

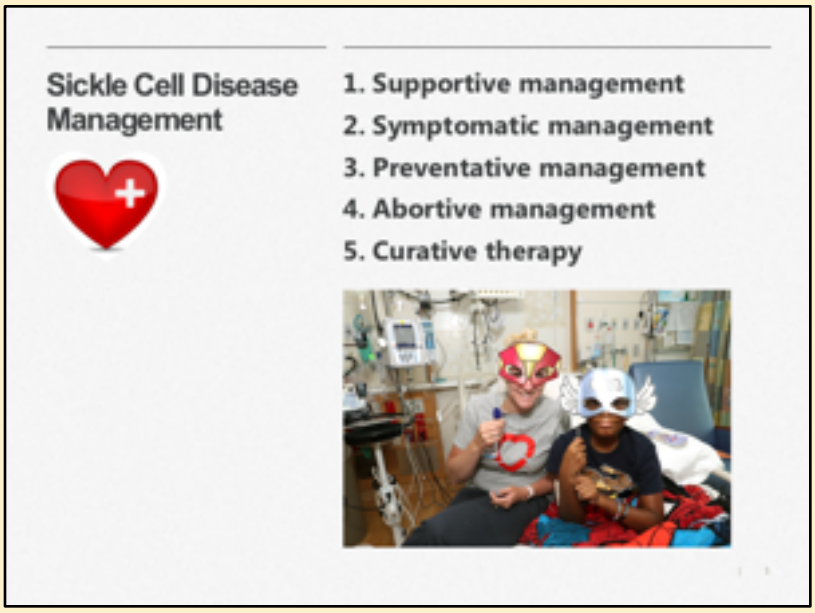
Select participants willing to share their answers to each question.
[Limit discussion to 2 minutes/question, 5 minutes total]

Potential answers:

- *Is this your usual SCD pain? Or is location or quality new*?
- *What usually works to treat his pain when it is this intense?*

[10 MINUTES of 45 minute session is complete]

PRN Program: SCD



ASK: How do you provide: **Supportive management**:

Select a participant willing to share their answer to this question.
[Limit discussion to 1 minute/question)

READ: *these Key points (**if not included by participant**):*
Maintain the essential requirements for good health, such as balanced diet, sleep, hydration, folic acid, & regular follow-ups

ASK: How do you provide: **Symptomatic management**:

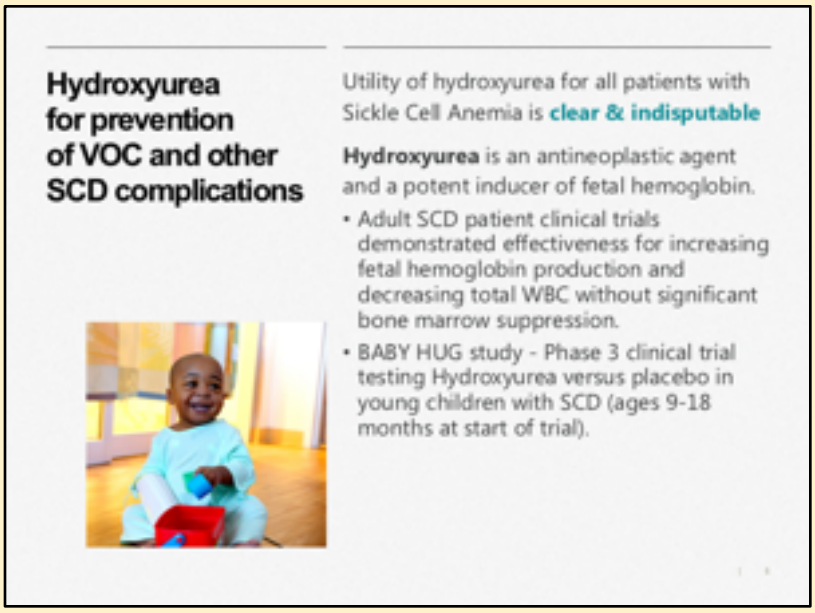
Select a participant willing to share their answer to this question. ***[1 minute)***

READ: *these Key points (**if not included by participant**):*
To alleviate symptoms as they occur, such as analgesics for pain and blood transfusions for symptomatic anemia.

READ:

Preventative management is to prevent complications, such as vaccinations to prevent infection & sepsis, teaching patients to avoid cold & stress, and providing HbF induction with hydroxyurea. **Abortive management** are efforts to abort painful crisis and prevent worsening conditions or precipitating complications. **Finally, Curative therapy** is limited to stem cell transplantation, although gene therapy remains a possibility.

PRN Program: SCD

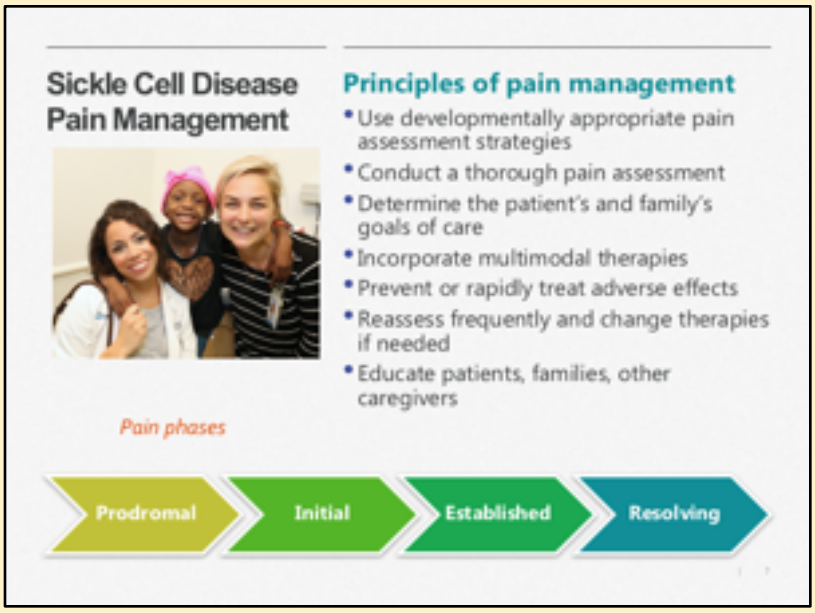


READ:

With documented efficacy and acceptable long-term safety profile, hydroxyurea treatment is considered standard of care for all young patients with SCD.

[15 MINUTES of 45 minute session is complete]

PRN Program: SCD



ASK: What are the goals of managing SCD associated pain?

Select participants willing to share their answers to this question. Write on flipchart or whiteboard ***[Limit discussion to 1 minutes]***

READ: *these Key points (****if not included by participants****):*

- *Prevent VOC*
- *Decrease pain*
- *Prevent/manage adverse effects associated with treatment*
- *Promote patient safety and function*
- *Enhance quality of life*

ASK: What is the significance of the pain phases with the principles and goals or pain management?

Select participants willing to share their answers to this question. Write on flipchart or whiteboard ***[Limit discussion to 1 minutes @ 15secounds/phase]***

READ: *these Key points (****if not included by participants****):*

1. Prodromal *phase lasts 1-2 days. Individuals with SCD describe symptoms of numbness, paresthesia or aches at the location of subsequent pain.*

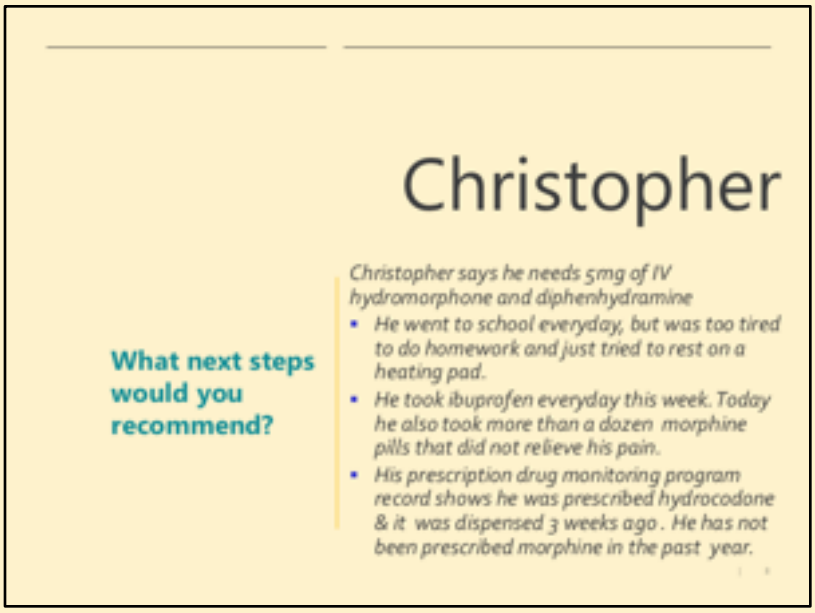
2. Initial *phase lasts about 2 days. Individuals with SCD report increasing pain. Inflammatory markers, like (erythrocyte sedimentation rate (ESR) & C-reactive protein (CRP)) are also increased.*

3. Established *phase lasts approximately 4 days and is associated with maximum pain severity, increasing ESR and peak CRP.*

4. Resolving *phase is characterized by lessening pain, ESR peak & decreasing CRP.*

Despite escalating doses of opioid analgesics, pain intensity scores do not significantly decrease during hospitalization.

PRN Program: SCD



READ:

Christopher reports that at home he took the pain control steps listed on this slide.

ASK: What would you recommend next?

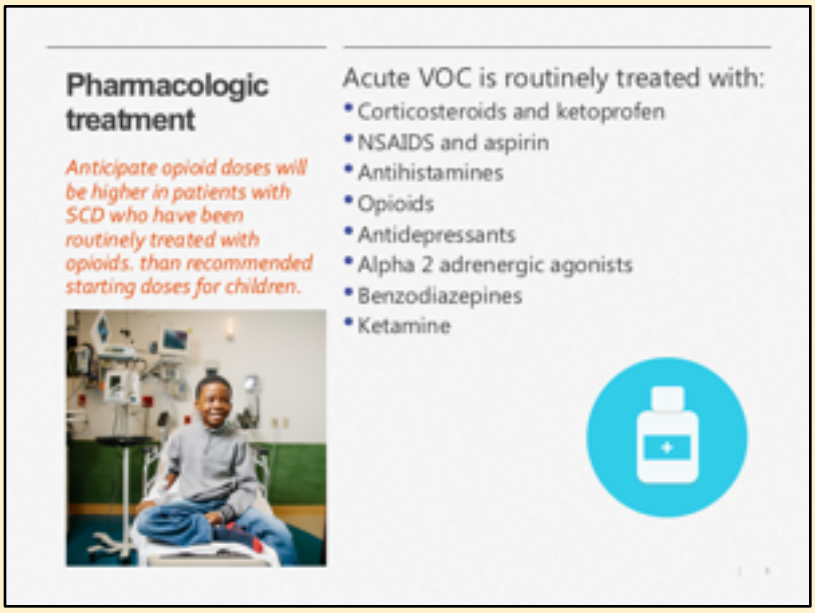
Select participants willing to share their answers to this question.

Write on flipchart or whiteboard

[Limit discussion to 3 minutes]

[20 MINUTES of 45 minute session is complete]

PRN Program: SCD

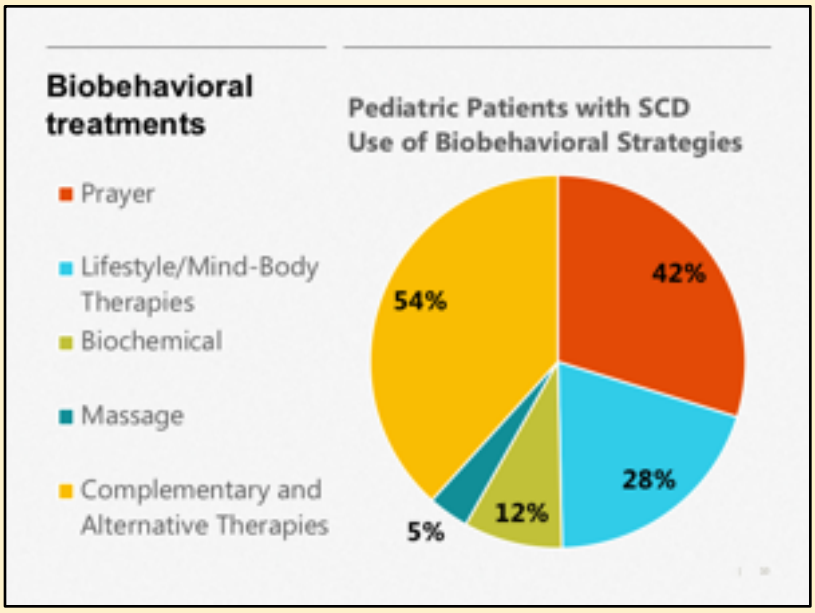


READ:

The NIH-NHLBI expert panel recommends for VOC pain management:

- Give IV analgesic within 30 minutes of triage or within 60 minutes of registration.
- Reassess pain and titrate opioid analgesics every 15-30 minutes until pain is under control.
- Since obtaining IV access may delay prompt treatment of severe acute pain, intranasal opioid administration with a particulate diffuser may be an acceptable alternative for the child with VOC.

PRN Program: SCD



READ: Biobehavioral treatments include:

Physical techniques:

- Heat
- Massage
- Transcutaneous Nerve Stimulation (TENs)

COLD is **contraindicated** and may precipitate VOC.

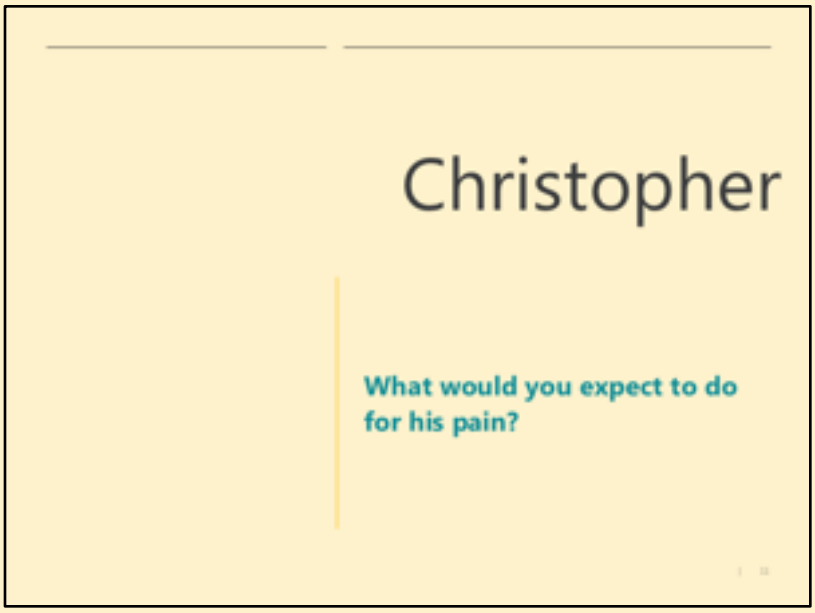
Cognitive/behavioral therapies:

- Relaxation/distraction/guided imagery/self-hypnosis
- Expressive arts/music
- Cognitive reframing
- Prayer
- Support from a friend/peer support/support groups

Coping strategies

- Some strategies put the child who is hurting in control and others are more passive techniques.
- Active coping involves doing something to help, like
  - Playing a video game
  - Listening to music
  - Gaining control - using positive self talk statements
  - Even, engaging others to get help

PRN Program: SCD



ASK: What would you expect to do for Christopher's pain?

Select participants willing to share their answers to this question. Write on flipchart or whiteboard ***[Limit discussion to 3 minutes]***

READ:

- Opioids & NSAIDs are the analgesics of choice for the treatment of pain from SCD.
- Start with a short-acting opioid and titrate aggressively until pain relief is obtained. For example, start with 15 mg of short-acting morphine, every 3 hours PRN. Convert to extended release morphine once the effective 24 hour dose of short-acting morphine is determined.
- It is essential to begin a bowel regimen, e.g., Mirilax or senna and titrate as needed to produce a daily bowel movement.

IN a secondary analysis of data from 204 youth (mean age 13.6 years) with pain from SCD who presented to 8 different EDs and were then admitted to the hospitals, earlier start of oral opioids was highly associated with shorter hospital lengths of stay and higher health-related quality of life.

[25 MINUTES of 45 minute session is complete]

PRN Program: SCD

READ: Pair up for this "Pair and share activity."
You have 2 minutes each to discuss how your personal experiences, beliefs, and attitudes influence your pain care for patients with SCD?

[Limit discussion to 4 minutes, announce switch at 2 minutes]

Select participants willing to share their answers. Write on flipchart or whiteboard labeled: ***Provider bias*** *&* ***Patient bias***

[Limit discussion to 5 minutes]

READ: *these Key points (****if not included by participants****):*

Provider bias: *Believing or not believing pain self report. Contributing factors:*

- *Racial or ethnic bias,*
- *High pain intensity scores with minimal outward signs of pain,*
- *Concern about drug addiction or drug seeking.*

VOC pain intensity judgement introduces bias that affects pain treatment.

Provider bias solutions, Recognize:

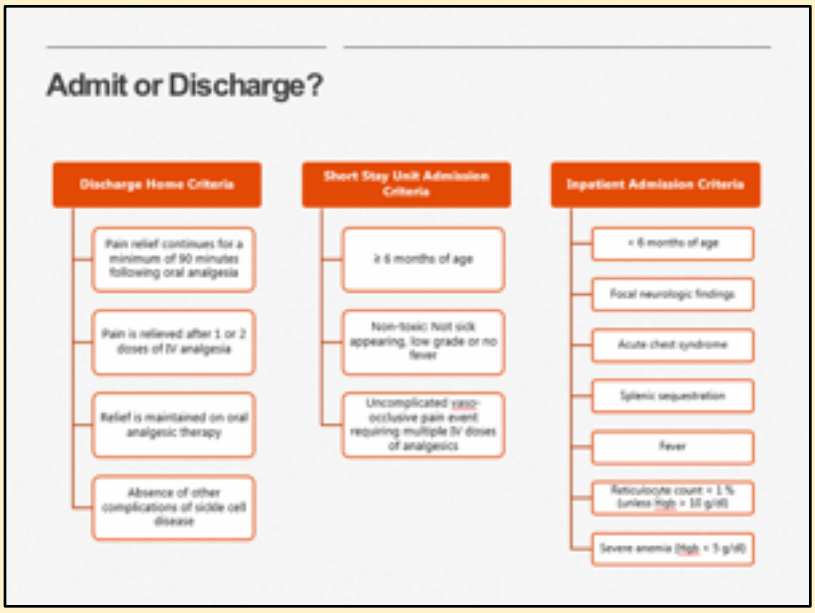
- *Bias creates lack of trust & poor communication of patient(s) & provider(s)*
- *Most patients try to manage their care at home and come to the hospital only as a last resort when in need of more pain treatment.*

Patient bias: *Because SCD pain is a life long condition, and episodes increase over time, consequences of inadequate care and distrust can build up.*

Patient bias solutions,

- *Consistent provider relationships,*
- *Consistent use of established evidence-based pain management protocols*
- *Individualize protocols for pain management*
- *Keep a home diary or record of how pain is managed at home prior to coming to the ED.*

PRN Program: SCD



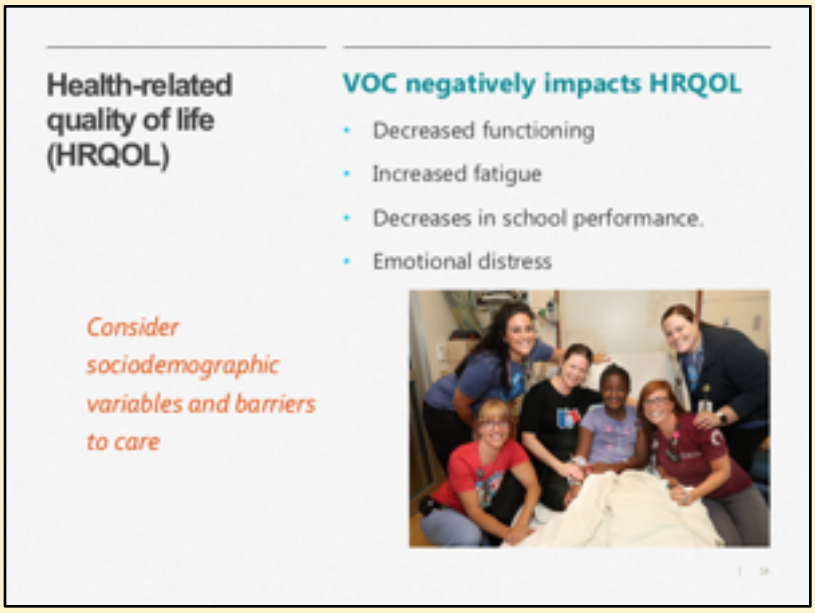
READ: Note that different hospitals may have different practices, but this is another solution to limit bias:

In some settings, there is an option for a short stay unit or day hospital setting, often open until 5 or 6 pm, where patients can be treated without hospital admission or overnight stay rather than in the ED.

These settings are focus on providing care to patients with VOC pain and are often staffed with clinicians who know the patients and their pain care.

[35 MINUTES of 45 minute session is complete]

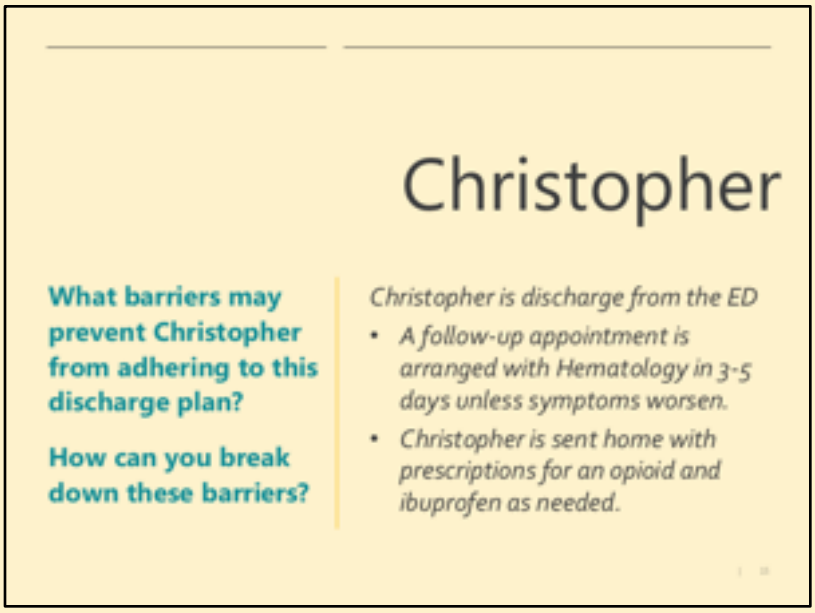
PRN Program: SCD



READ:

Painful SCD VOC negatively impacts Health-related quality of life

PRN Program: SCD



ASK:

What barriers may prevent Christopher from adhering to this discharge plan? And how can you break down these barriers?

Select participants willing to share their answers to this question.
Write on flipchart or whiteboard
[Limit discussion to 2 minutes]

READ: *these Key points (**if not included by participants**):*

- Current climate about opioid abuse and diversion must be considered.
- Issues relevant to patients with SCD separate from other populations are real and related to poverty, including access to treatment, attitudes and beliefs of caregivers, documented inadequate pain treatment of those from minority populations.
- For Christopher, access to medication in the community where he and his mother live may be difficult

PRN Program: SCD

ASK: What education should be provided?

Select participants willing to share their answers to this question.
Write on flipchart or whiteboard
[Limit discussion to 2 minutes]

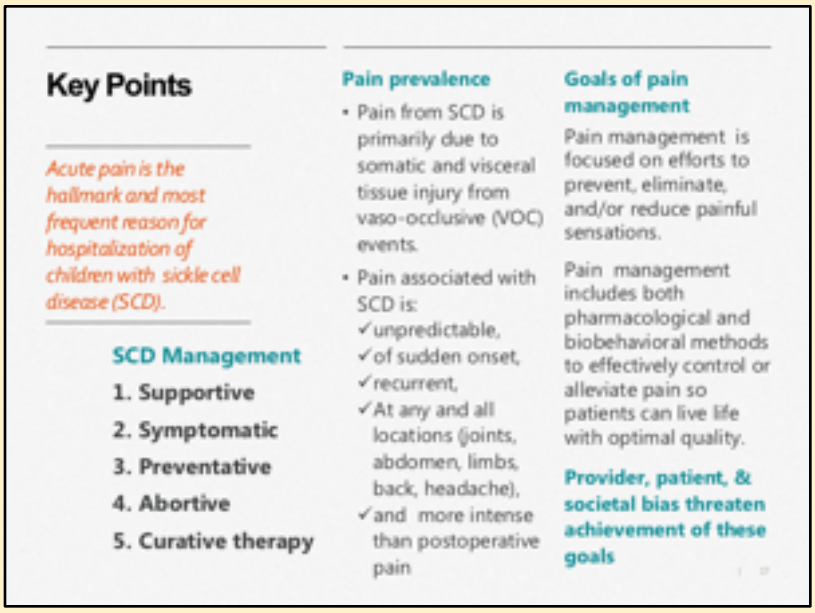
READ: *these Key points (**if not included by participants**):*

- *Safety issues regarding storage of opioid analgesics and other drugs should be addressed.*
- *Teach additional age appropriate ("new")coping skills to help his HRQOL (guided imagery).*
- *Education should include written instructions about Christopher's analgesic plan and contact information for healthcare professionals should he or his mother have questions about his diagnosis and treatment plan.*
- *Resources that might provide assistance with coping:*

Starlight Children's Foundation *https://www.starlight.org/*
Sickle Cell Kids *http://Sicklecellkids.org*
University of Michigan Medicine: Pain in Sickle Cell Disease
http://www.med.umich.edu/yourchild/topics/sicklecell.htm

[40 MINUTES of 45 minute session is complete]

PRN Program: SCD



Key Points

Acute pain is the hallmark and most frequent reason for hospitalization of children with sickle cell disease (SCD).

SCD Management

1. **Supportive**
2. **Symptomatic**
3. **Preventative**
4. **Abortive**
5. **Curative therapy**

Pain prevalence

- Pain from SCD is primarily due to somatic and visceral tissue injury from vaso-occlusive (VOC) events.
- Pain associated with SCD is:
  - ✓unpredictable,
  - ✓of sudden onset,
  - ✓recurrent,
  - ✓At any and all locations (joints, abdomen, limbs, back, headache),
  - ✓and more intense than postoperative pain

Goals of pain management

Pain management is focused on efforts to prevent, eliminate, and/or reduce painful sensations.

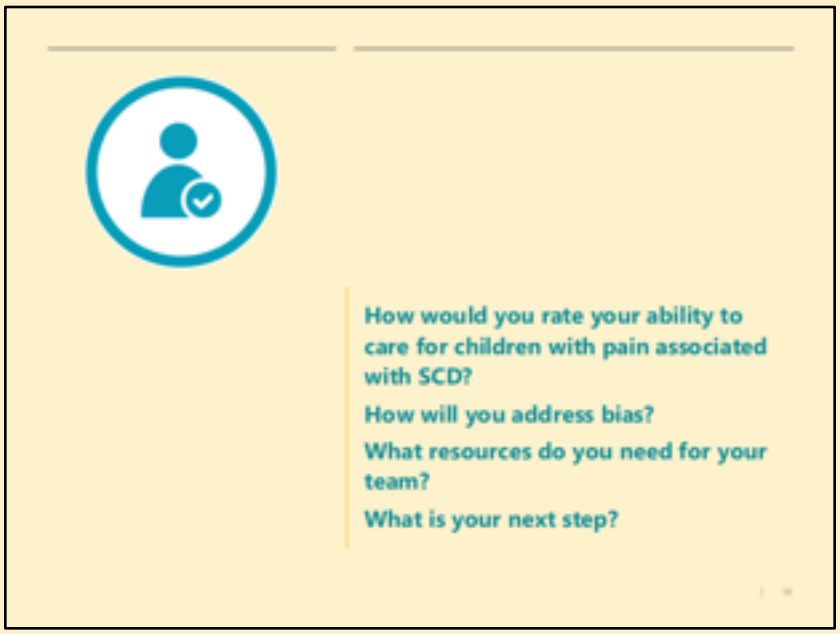
Pain management includes both pharmacological and biobehavioral methods to effectively control or alleviate pain so patients can live life with optimal quality.

Provider, patient, & societal bias threaten achievement of these goals

ASK: Are there any questions?

[Limit to 3 minutes]

PRN Program: Assessment of Pain



[45 MINUTE SESSION COMPLETE]