

**Vision of Hope: Integrating Pediatric Palliative Care into Chronic Disease
Sickle Cell Disease**

One Day at a Time

For SCD Specialists:

What one thing stood out for you as relevant/important in enhancing quality of life for patients with SCD?

For Other Clinicians:

You usually see patients with SCD when they are in crisis or not feeling well. After watching the film, did anything surprise you about the experiences of young people living with SCD?

For Everyone:

How might a palliative care approach enhance the quality of life for adolescent patients with sickle cell disease?

They Don't Believe Me

For SCD Specialists:

Is there anything in your own practical experience or education and knowledge about SCD that could explain why clinicians might not believe some patients with SCD when they talk about their experiences or their pain?

For Other Clinicians:

Did you see anything in this film that surprised you about the experiences that patients with SCD have when seeking health care for their pain, and/or about the attitudes/role of clinicians in pain management?

For Everyone:

What would need to happen for clinicians to respond differently to the suffering

experienced by adolescents living with sickle cell disease?

Trust

For Everyone:

Based on what you saw in this film and your own experience, what specific behaviors build or break trust between SCD patients, families and clinicians?

How might a palliative care approach help to build trust in patient and clinician relationships?

Navigating the Hard Times

For Everyone:

Based on this film, what are the sources of patient and family suffering that might be overlooked?

Besides prescribing medicine, what are the ways clinicians can address suffering and support the inner resilience of patients with SCD?

General Discussion

Regarding what we have discussed during today's session, what change would you like to see/make in your own practice?

Are there unmet needs in the care of adolescent patients with sickle cell disease that a palliative care approach could help to address?