Effective Health Care

Comparative Effectiveness of Sickle Cell Disease Centers Versus Current System of Episodic Care Nomination Summary Document

Results of Topic Selection Process & Next Steps

- The topic area, *Comparative Effectiveness of Sickle Cell Disease Centers Versus Current System of Episodic Care*, is not feasible for a full systematic review due to the limited data available for a review at this time.
- This topic area could potentially be considered for new research in comparative effectiveness.

Topic Description

Nominator(s): Individual

Nomination Summary: Adults with sickle cell anemia (SCA), the most common form of sickle cell disease (SCD), require regular and ongoing medical care for treatment of symptoms and prevention of complications of the disease. The care may be delivered by specialists in hematology. Care may be delivered across a variety of settings by different providers with differing expertise and experience in caring for individuals with sickle cell anemia This has the potential to fragment care, and result in lower quality of care. A center of excellence, which can deliver care in one setting, has the potential to help improve management and treatment of patients with SCD and thereby improve patient outcomes. A systematic review on the subject could help inform decisions about how to best deliver care for adults with SCD.

Staff-Generated PICO
Population(s): Adults with SCD
Intervention(s): Sickle Cell Center of Excellence
Comparator(s): Usual care
Outcome(s): Morbidity, mortality, quality of life, ED utilization, incidence of acute pain crises

Key Questions from Nominator: For adult patients with SCD, what is the comparative effectiveness and cost-effectiveness of providing care at a sickle cell center of excellence compared to usual care?

Considerations

- Sickle cell disease (SCD) is an inherited hematologic disorder characterized by a tendency of red blood cells to “sickle” or become misshapen as a result of particular stresses. These abnormal cells become clogged in blood vessels and are hemolyzed as a result, causing anemia. Furthermore, red blood cells,

when misshapen, can be caught in small blood vessels causing pain, infection, strokes, and other organ damage.

- Adult SCD patients require ongoing medical care to prevent complications and treat symptoms. They may seek care at an emergency department (ED) for acute complications, such as a pain crisis. Furthermore care may be delivered by providers with different levels of experience and expertise in caring for individuals with SCD. The potential for fragmented care, may result in poorer outcomes and increased costs.
- Treatment in a SCD center of excellence may have the potential to improve outcomes for adult patients with SCD by providing coordinated high-quality care to meet their specialized needs.
- Although we identified guidance about treatment for SCD patients, we did not identify guidance specifically about the delivery of care through a center of excellence focused on SCD in adults.
- A search of the literature did not yield any directly relevant studies; the most closely relevant studies examined the benefits of using multidisciplinary teams to provide care for patients with SCD. Most studies focused on the delivery of care to pediatric patients or focused solely on the inpatient or ED settings. Therefore, this topic area is not feasible for a full systematic review due to the limited directly relevant primary research available at this time. New research focused on primary care for adult SCD patients, including the comparative effectiveness of care received through an SCD center of excellence versus usual care, may be helpful.