2022 LEAD Capstone Poster Session

Transitioning from Good to Great:
A Vision for the Next Level of Sickle Cell Care

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Abstract

- Pediatric to adult transfer is a period of care noted to have increase mortality in patients with sickle cell disease (SCD). [1]

- Transition Programs are felt to be a good way to address this national crisis for these high risk patients.

- A recent consensus on essential criteria of SCD programs provide some guidance and endorse development of dedicated SCD centers.[2]

- Innovative care models are needed ensure safe, accessible, equitable, experienced care continuity while addressing ongoing healthcare disparities for patients with SCD.

Objectives

- Describe the UT Southwestern Medical Center (UTSW) landscape of current care for patients with sickle cell disease (SCD)

- Identify strengths and weaknesses of the current care model

- Propose alternate care model

- Identify stakeholders for this initiative

Background Information

- SCD is a blood disorder that has severe medical complications of every organ system.

- Average life expectancy for patients with the most common genotype is significantly shortened compared to unaffected comparator groups.[3]

- Access to comprehensive, multidisciplinary experienced care is lacking, particularly for adult patients which likely contribute to the poor outcomes.[2]

- UTSW has experienced pediatric and adult SCD programs with a focused Transition Program.

Background Information

- Despite the advantage of having a SCD Transition Program, care access remains a challenge and cost of care for young adults remains excessive. National estimates exceed $2 billion annually due to high Emergency Department and inpatient admissions.[4]

- UTSW is primed to be a leader in the creation of a unique alternate care model aimed to improve quality of care, care access and decrease ED/inpatient admissions.

- Currently, there are other clinics attempting to create Lifespan Clinics but none with the UTSW advantage of dedicated pediatric and adult teams.

Project Plan

- Identify Potential Stakeholders:
  - Rare Disease Center of Excellence-UTSW earned designation in 2021 by the National Organization of Rare Disorders (NORD)
  - UTSW, Parkland and Children's Health Leaders in:
    - Quality
    - Hospital
    - Ambulatory
    - Diversity
  - UTSW and Children's partnership in building new pediatric hospital that are geographically connected
  - Informatics to streamline Epic communications within the electronic medical record since all use this similar platform

Project Plan

- Create a SCD Multidisciplinary Lifespan Clinic to meet the care needs starting in pediatrics through adulthood
- Anticipated benefits:
  - Streamline communication and workflow between the experienced SCD teams
  - Improve quality of care and decrease healthcare inequities/disparity
  - Decrease excessive cost of care to the participating organizations
  - Remove the potential of “losing” patients during the “transfer of care” since the care remains in same geographic location
  - Consolidate the resources currently allotted to pediatric and adult SCD programs

Application of What You Learned at LEAD

- Identify how my work aligns with UTSW mission
- Identify and engage collaborators
- Understand how my work may affect other initiatives or considerations of my immediate supervisors (i.e. competing interests) when presenting a proposal

Innovation and Significance

- This is a proposal of true innovation within the UTSW Medical Center as no such structure currently exists.

- UTSW could be a national leader to show success in such a model that is not described elsewhere for advancing the care of patients with SCD.

- Success of a SCD Lifespan Clinic can be a model for other complex rare diseases that face similar challenges (e.g. congenital heart or cystic fibrosis patients).

References

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4. Lanzkron S, Carroll CP, Haywood C Jr. The burden of emergency department use for sickle-cell disease: an analysis of the national emergency department sample database. Am J Hematol. 2010;85(10):797-799.