

Improving Sickle Cell Transition from Pediatric to Adult Care



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BACKGROUND

- Over 5,500 individuals with sickle cell disease (SCD) in North Carolina.
- There is an increase in Emergency Department and inpatient utilization during the transition from pediatric to adult care.
- Management of SCD should address patients' health literacy, health behaviors, and socioeconomic factors to align for the best health outcome.

PROJECT AIM

- By 8/1/2024, 80% of patients 13+ years old with SCD at ECU Health Pediatric Hematology/Oncology clinic will have the transition checklist implemented into their patient care.

PROJECT DESIGN/STRATEGY

- All patients with SCD aged 13+ years old presenting to the clinic will receive a transition checklist and pre-checklist survey.
- The pre-checklist survey will assess comfort levels with checklist topics. The transition checklist contains three categories with discussion topics for the patient and providers.
- Upon finishing the checklist, patients will complete a post-checklist survey to reassess their comfort level with the completed topics.

CHANGES MADE (PDSA CYCLES)

Phase I

For each of the questions below, circle the response that best characterizes how you feel, where 1 = Very uncomfortable, 2 = Somewhat uncomfortable, 3 = Neutral, 4 = Somewhat comfortable, 5 = Very comfortable

How comfortable do you feel....

	Very Uncomfortable	Somewhat Uncomfortable	Neutral	Somewhat Comfortable	Very Comfortable
1. Explaining what sickle cell disease is?	1	2	3	4	5
2. Knowing what triggers your pain?	1	2	3	4	5
3. Sharing your diagnosis with others?	1	2	3	4	5
4. Identifying your social support network?	1	2	3	4	5
5. Explaining how hydration, exercise, and stress management can impact your health?	1	2	3	4	5

Example A. Phase I Pre-Checklist Survey

Phase I

Healthcare	Health Behaviors	Socio-economic Factors
<input type="checkbox"/> Intro to SCD <input type="checkbox"/> Genetics <input type="checkbox"/> Fever & SCD <input type="checkbox"/> Anemia <input type="checkbox"/> Pain triggers <input type="checkbox"/> Important lab values and meaning behind them <input type="checkbox"/> Disease complications	<input type="checkbox"/> Hydration <input type="checkbox"/> High risk pregnancy <input type="checkbox"/> Self-advocacy <input type="checkbox"/> Sharing diagnosis w/ others <input type="checkbox"/> Stress reduction <input type="checkbox"/> Peer pressure <input type="checkbox"/> Behavioral pain management, gate control theory of pain, etc. <input type="checkbox"/> Starting to increase independence and manage your own medications/healthcare <input type="checkbox"/> Importance of physical activity	<input type="checkbox"/> Identifying support networks <input type="checkbox"/> Short- / Long- term academic and career goals <input type="checkbox"/> Assessment of home life challenges

Example B. Phase I Transition Checklist

FUTURE RESULTS/OUTCOMES

- The percentage of patients with the transition checklist implemented into their patient care and the pre-and post-transition checklist survey results will be measured to test the impact of the transition checklist on patients' comfort levels on topics of their health, health behaviors, and socioeconomic factors.

LESSONS LEARNED

- Currently, the clinic does not have a standardized process to prepare patients for transition to adult care.
- Monthly meetings with clinic staff will be necessary to evaluate opportunities for improvement so that the project is successful for both patients and the clinic.

NEXT STEPS

- The clinic has plans to implement the transition checklist in February 2024.
- Implementing a standardized transition checklist for pediatric patients with SCD may lead to improved patient adherence, experience, and long-term health outcomes while in adult care.

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