

Prompting for Precision: The Role of the Patient Voice in Developing a Measure of Transition Readiness for Adolescents and Young Adults with Sickle Cell Disease

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INTRODUCTION

- The highest rate of morbidity and mortality in adolescents and young adults (AYA) living with sickle cell disease (SCD) occurs during the transition from pediatric to adult care
- This study aimed to conduct cognitive interviews with AYA with SCD to elicit their feedback on items developed for the Transition Readiness Inventory for SCD (TRI-SCD)
- Cognitive interviews are a key step in rigorous methods of developing valid patient-reported outcome measures
- Transition Readiness refers to indicators that patients and those in their support system can begin, continue, and finish the transition from child-centered to adult-oriented healthcare through the event of transfer

METHODS

- AYA with SCD (ages 16-29) at the Children's Hospital of Philadelphia were asked to complete the TRI-SCD item pool, which consisted of 80 items that assessed multiple domains of transition readiness
- After completing the total item pool, cognitive interviews (on 20 items/participant) were conducted to understand participants' interpretation of items, content and clarity, response selection, and how the items could be improved

Table 1. Cognitive Interview Probe Examples

Standard Probe	"In your own words, what is this item asking?"
Item-specific Probe	"What did you think of when you read the word, medication?"

RESULTS

- Thus far, 4 cognitive interviews using the same 20-item set have been conducted with 2 female and 2 male African-American participants (ages 21 to 26)
- AYA reported similar feedback for items related to knowledge, skills, maturity, and goals

Table 2. TRI-SCD Items and Associated Participant Ratings and Interpretation

TRI-SCD Item	Participant Ratings & Interpretations of Key Constructs
I know the names of the medications I take for sickle cell disease.	Ratings: Agree a lot Consensus Interpretation: Daily pills that they take at home
I am comfortable talking to the emergency room team when I am in pain.	Ratings: Agree a lot Interpretation A: Relationship lens with an emphasis on the word "comfortable." Her comfort depended on who she was interacting with and how much she trusted that team. Interpretation B: Physical capability lens with an emphasis on the word "talking." This AYA often has so much pain that it is difficult to speak, so his communication is dependent on how much pain he is experiencing and not about his relationship with the care team.

DISCUSSION

- Cognitive interviews will continue for the purpose of advancing the item pool so that it accurately assesses transition readiness in this population
- The development of the TRI-SCD is crucial to identify and target the barriers that bar successful transition to adult-care for AYA with SCD and to mitigate health inequity and achieve more favorable health outcomes



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Creating a validated measure of transition readiness for AYA with SCD is key to identifying barriers and improving health equity.



Cognitive interviews are vital in measurement development to learn about the experiences of AYA with SCD as their voices are crucial in developing valid patient-reported outcomes (PROs).

Exemplar Items from The Transition Readiness Inventory for SCD (TRI-SCD)

Knowledge & Health Literacy



I know the amount (dose) of each medication I take for sickle cell disease.

Skills & Self-efficacy



Who is most likely to schedule your sickle cell appointments?

Developmental Maturity



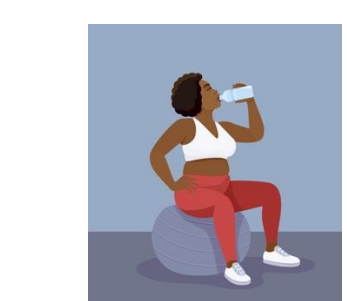
I am mature enough to manage my healthcare on my own.

Beliefs & Expectations



When it comes to my sickle cell care, an adult sickle cell team will be as caring as my pediatric sickle cell team.

Goals & Motivations



My goal is to be pain-free.

Relationships & Communication



I am comfortable telling my sickle cell team if I disagree with them.

Emotions & Psychosocial Functioning



When I think about transferring to an adult provider, I feel overwhelmed.