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ORAL ABSTRACTS

901.HEALTH SERVICES AND QUALITY IMPROVEMENT - NON-MALIGNANT CONDITIONS

Trainees' Perspectives on Components of Sickle Cell Specific Education

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Background
Sickle cell disease (SCD) is at the intersection of social, racial, and healthcare equity in the US. It is a socially and medically complex disease associated with increased morbidity and mortality when compared to age, race, and sex matched persons without SCD. Despite a historically high prevalence, it has not been a priority in healthcare, which contributes to healthcare inequities in this population. Patients and clinicians consistently identify lack of clinician knowledge about SCD as a barrier to quality care. Providers describe discomfort managing patients and have a poor understanding of its complications. The number of physicians trained and available to treat adults with SCD is insufficient to meet population needs. With most hematology/oncology trained physicians choosing careers in oncology, the pool of practitioners with expertise in SCD is shrinking. This underscores the time-sensitive need for building an effective, sustainable, and patient-centered sickle cell educational curriculum early in training. At present, there is no widely used resource for SCD-specific education, and little research has been published describing physician education for this complex disease. This qualitative study is the first part of a two-part study which aims to serve as a needs assessment to understand the SCD specific educational demands of trainees and set the stage for survey development for wider distribution.

Methods
Residents applying for hematology/oncology fellowship and current fellows were recruited to participate in focus groups to explore trainees' preferences and attitudes for education on the management of patients with SCD. Trainees were recruited via email from seven academic institutions in the US from regions with a high prevalence of SCD. A focus group guide was developed inquiring about trainee perspectives on facilitators and barriers to obtaining sickle cell specific education. Using an inductive and iterative thematic analysis coding approach, all focus group transcripts were coded by an academic hematologist specializing in SCD (LV) and an academic psychiatrist specializing in SCD (EP). Codes were categorized and themes and subthemes developed.

Results
Four focus groups were conducted with a total of 15 participants (2 PGY 3 residents, and 13 hematology/oncology fellows PGY 4-6). Three themes were identified (Table): 1. **Discomfort caring for patients with SCD.** Trainees experienced feelings of fear, frustration, and powerlessness when caring for patients with SCD. **2. Challenges managing SCD.** Trainees described the complexity of SCD management, limited treatment options and evidence-based practice, and navigating bias in healthcare as contributing to the challenge of treating patients with SCD. **3. Desire for SCD specific education during fellowship.**Trainees noted ideal components of education should include exposure to patients longitudinally and in multiple settings, access to SCD expertise in the form of experts and expert guidelines, and SCD specific didactic content.

Conclusions
This study examined the experience of trainees with regards to SCD education and clinical care. Participants described how a lack of SCD specific education reinforced a cycle of discomfort and difficulty caring for patients with SCD (Figure). Lack of exposure to patients and access to experts impedes developing a sense of mastery in treating SCD. SCD education was underemphasized even at institutions with a high prevalence of SCD and a SCD program. Evidenced-based guidelines based on low evidence hinders self-directed learning. Overall, SCD specific education is under-emphasized in fellowship. Trainees who felt the most comfortable had a SCD specific curriculum integrated throughout the fellowship experience. A SCD specific

curriculum in the form of case-based didactics and a SCD rotation, where feasible, should be built into hematology/oncology fellowship training to increase trainees' knowledge, comfort and therefore desire in caring for patients with SCD. This qualitative research study is the first of its kind and serves to set the stage for survey development to capture a larger needs assessment of the SCD specific educational demands of hematology/oncology fellows. Optimizing the care of persons with SCD requires a competent and confident workforce. This study provides key insights into the development of infrastructure to support such training.

Disclosures Van Doren: *Pharmacosmos Inc:* Honoraria; *Pfizer:* Speakers Bureau; *Daiichi Sankyo:* Ended employment in the past 24 months; *Sobi:* Ended employment in the past 24 months; *Sanofi:* Ended employment in the past 24 months; *GBT:* Ended employment in the past 24 months.

Trainees Experience Discomfort Caring for Patients with SCD "I also don't want to do the wrong thing. It makes it less comfortable, and then it becomes less desirable."	**Fear and Uncertainty** "If it's the middle of the night and I get a page and it's a sickle cell patient from the ER I'm afraid because I don't know if I'm going to know what to do." "You're always operating in a gray area and never feel like you have a handle about what's going on."	**Frustration** "The frustration that I feel with seeing patients with SCD comes from a sensation that I don't have something to offer… that's going to solve the problem that they feel is the biggest for them. I can address some of the multisystem issues, and I can try to address the pain and at the end of they day, they're still going to be feeling like we haven't fixed the problem. And that's true, we haven't fixed most of it"	**Powerless** "We have these patients who are admitted over and over and over again… it's so sad to see and we really don't know how to help them in meaningful ways… I feel more helpless when it comes to caring for these patients" "Feeling in some ways powerless to take away some of they pain that they experience, and feeling a little bit intimidated about the best way to approach it."
Trainees Find SCD Management Challenging "It impacts so many different parts of their lives"	**Complexity** "There are a lot more decision-making points in terms of management." "The physiology is complicated. They have a lot of things going on… there's more sensitivity there"	**Limited Treatment Options and Evidence** "There's a lot less research and data behind treatments for sickle cell in general, in comparison to something like CHF." "There's so much variation in practice… because there's such a lack of evidence."	**Bias in Healthcare** "So much more of caring for patients is… dealing with the healthcare system a lot more than with a lot of other diseases"
Trainees Desire SCD Specific Education "SCD is one of the diseases that is most different on paper than in person. The most useful experience as a fellow has been immersing [myself] in sickle cell."	**Exposure to Patients** "More exposure would definitely have made me more comfortable" "There has to be some better mechanism for us to have long term relationships with patients"	**Access to SCD Expertise** "The most important thing for me is to have access to providers where this is their area of expertise." "More than following an algorithm on paper… I would say the expert's opinion matters more"	**Didactics** "I don't recall ever having any formal didactic [for SCD]." "Didactics are especially helpful in this area, where there's so much ambiguity."

Table 1. Trainee perspectives: themes and subthemes of challenges and components of sickle cell disease education

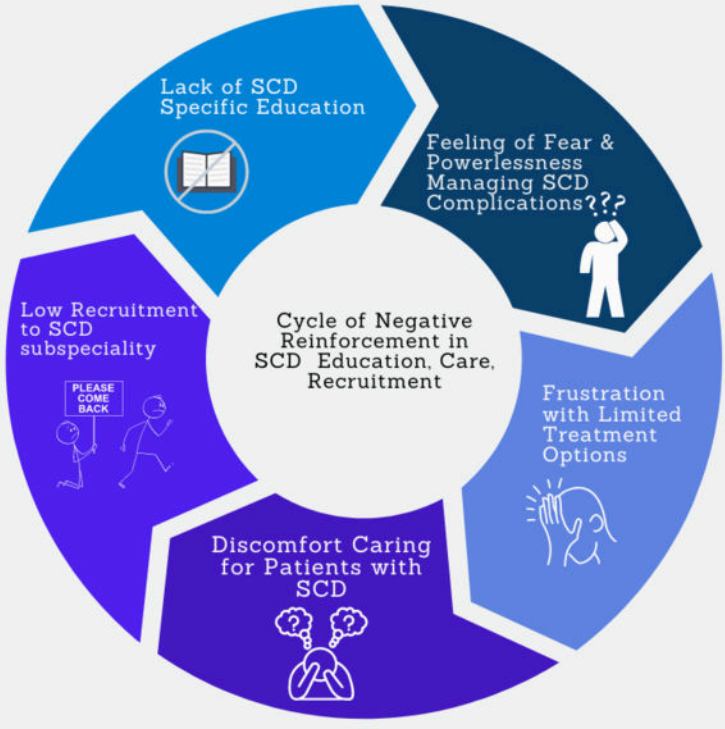

Figure 1. Cycle of negative reinforcement in SCD education, care, recruitment

Figure 1

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