

Improving Health Literacy, a Powerful Tool for Caregivers and Patient with Sickle Cell Disease

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Background

Gaps in health literacy could negatively impact the quality of life and care of individuals with sickle cell disease (SCD). Some potential gaps are management of the needs specific to their condition, recognizing critical signs and symptoms of possible complications, discussing benefits and risks of medications, and understanding barriers to care. Limited health literacy is associated with poor outcomes in chronic diseases. By providing age-appropriate educational materials during their scheduled clinic visits, we expect to increase caregivers’ and patients’ health literacy about SCD.

Objectives

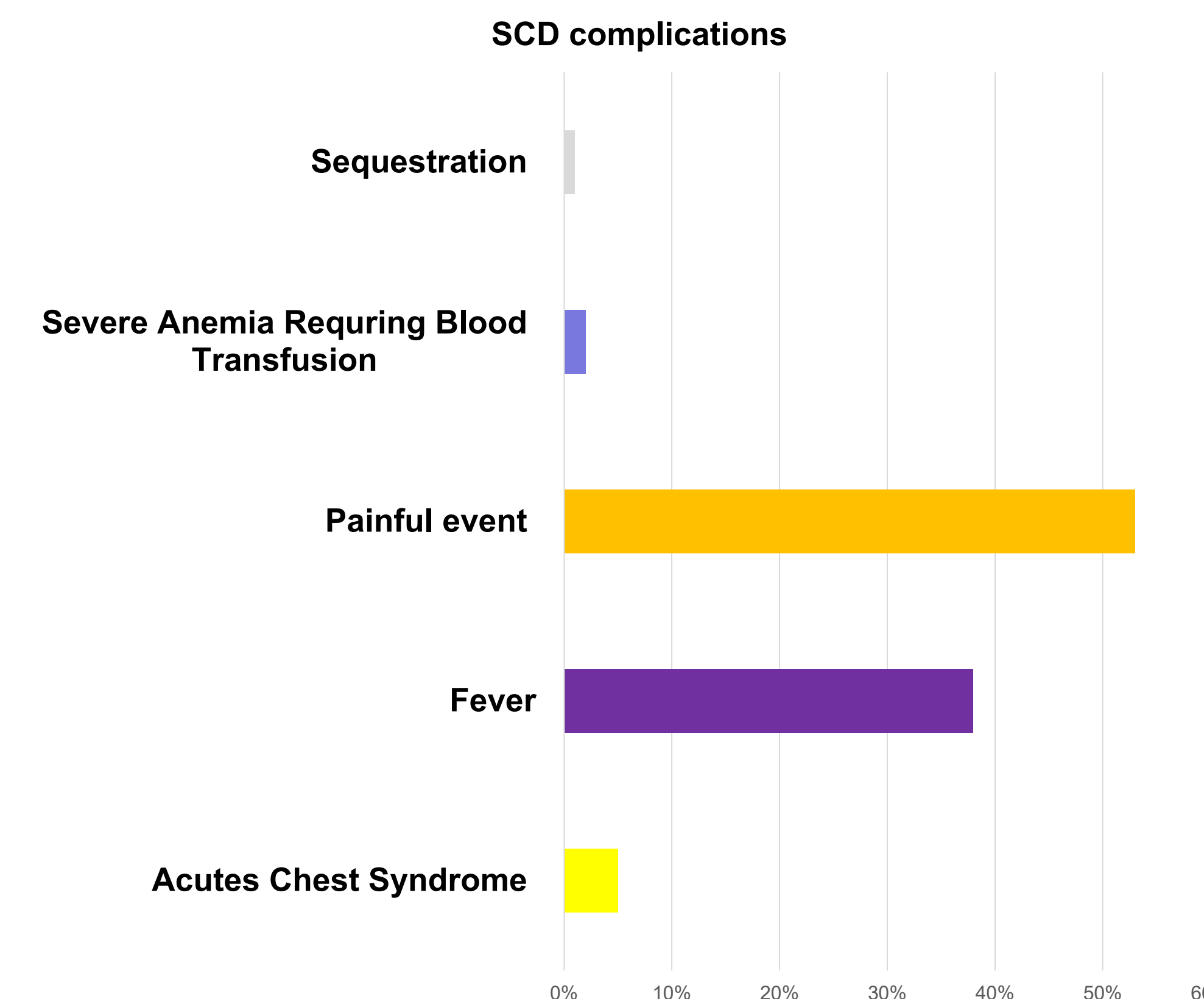
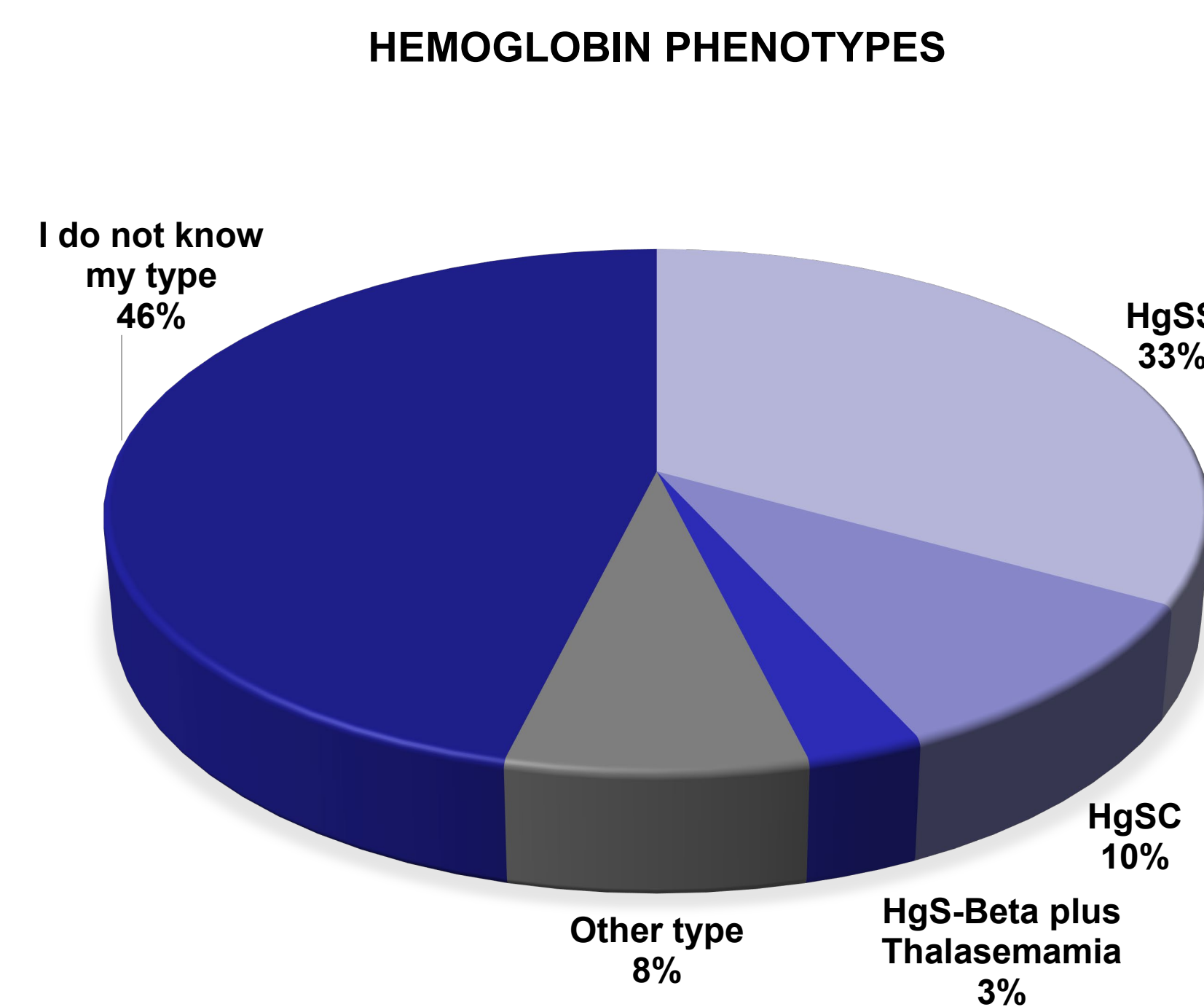
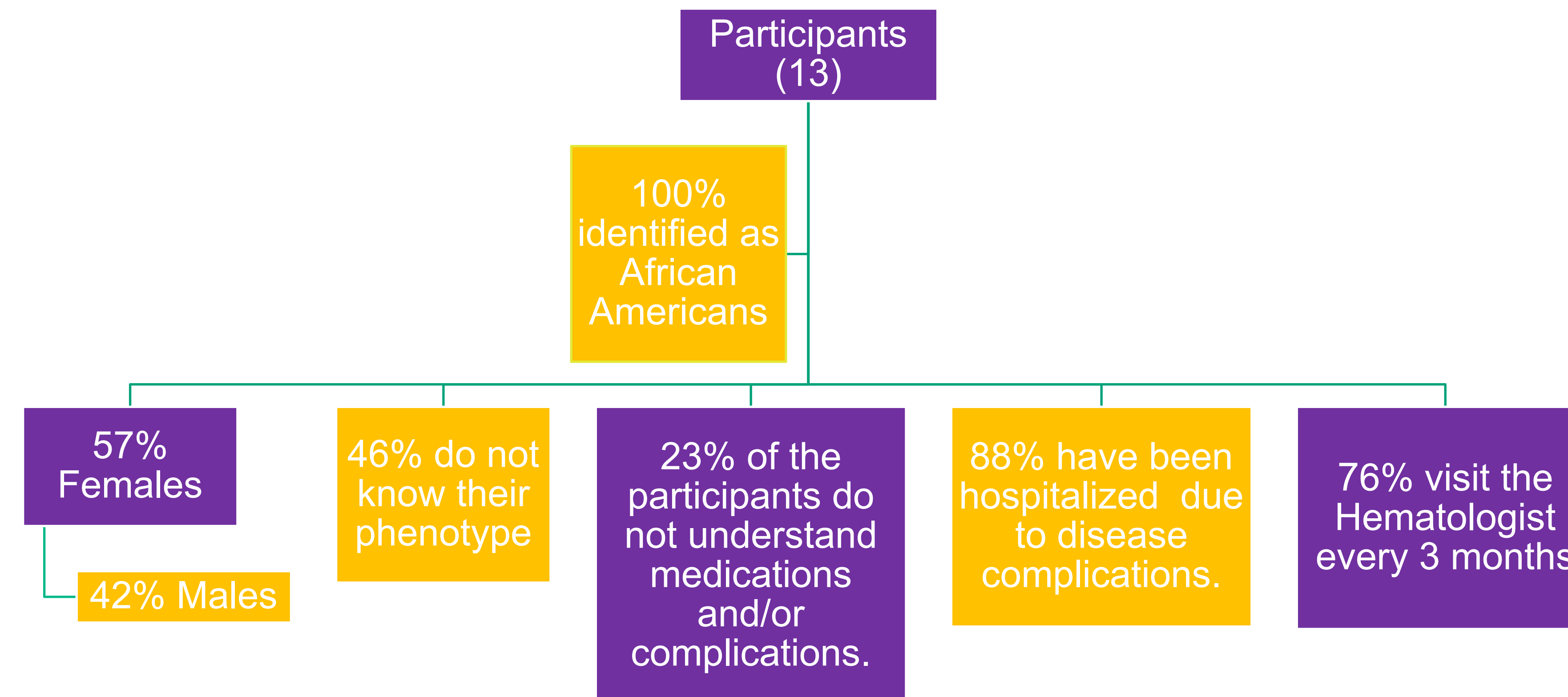
Aim 1: Assessing patient/caregivers understanding of their disease, prescribed medications, potential complications and long-term sequelae.

Aim 2: Improving health literacy by incorporating consistent educational tools into routine clinic visits

Methods

- A 17-question survey was distributed to caregivers of pediatric SCD patients or adolescent/young adult patients (*provide age cutoffs*) assessing their level of basic understanding of their genetic diagnoses, the purposes of prescribed SCD-related medications, potential SCD complications, and other assessments of disease status.
- Surveys are administered using electronic tablets during clinic visit.
- Subsequently, patients and/or caregivers are introduced to a series of educational materials via a 1-year standard curriculum comprised of a series of video modules reviewed during routinely scheduled clinic appointments.
- A follow up survey and assess literacy tools would conduct at the completion of all educational modules with to assess changes from baseline health literacy.

Results



Overall, 90% of the patients and caregivers are interested in receiving further education in SCD.

- Electronic device being their preferred method of delivery.
- Interactive webinars
- More time with the doctor and nurse educator in SCD.

Conclusions

- A portion of our patient population lacks an adequate understanding of their disease.
- By using consistent educational tools, individuals indicated satisfaction with the material provided as well as the vehicle (videos via electronic device).
- Many families expressed interest in reviewing further educational materials beyond this series.
- Our goal is to increase health literacy, thereby empowering individuals to better manage their disease and advocate for themselves or their child.
- Optimizing health literacy in the setting of chronic illness improves clinical outcome and quality of life, lowers dependence on healthcare services, and extends life expectancy.

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