

Nutrition Needs Assessment for Patients with Sickle Cell Disease Throughout the Lifespan

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Objective: Patients with sickle cell disease (SCD) experience a range of debilitating symptoms, as well as structural barriers like limited access to education, healthcare, and adequate nutrition. Both macro- and micro-nutrient deficiencies are common and can further exacerbate the severity of SCD symptoms. Despite this, there is a notable lack of targeted nutritional interventions for individuals living with SCD. This research aims to identify gaps in nutritional knowledge among patients and caregivers, with the goal of informing those delivering effective, patient-centered nutrition education interventions. **Methods:** An anonymous RedCap questionnaire was administered to caregivers and patients with SCD at pediatric and adult SCD specialty clinics in 2024. The questionnaire consisted of nine nutrition-related questions using Likert scaling and was created by the research group. Participants were recruited for focus groups during which participants completed a semi-structured interview, building on themes of interest identified in the questionnaire. **Results:** Thirty-seven participants completed the initial questionnaire. The respondents endorsed an interest in learning more information about the relationship between nutrition and SCD; approximately 78% of respondents agreed or strongly agreed. Additional data analysis is ongoing and will be completed shortly. **Conclusion:** The results of this research provide valuable insight into the preferences of SCD patients and caregivers for nutrition education. Both the questionnaire and focus group showed a strong understanding of the importance of nutrition in disease management. Patients and families universally desire more nutritional education. Despite this similarity, there was a difference in the methods preferred by the questionnaire and focus group individuals. The individuals who completed the questionnaire preferred virtual methods, while the focus group individuals more strongly preferred in-person group sessions. These results are valuable in understanding the needs of the SCD population and serve as an important foundation for designing and implementing interventions that directly benefit the patient and caregiver community.

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