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

Exploring the Experiences of Pediatric Patients with Sickle Cell Disease and Their Families

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Background: Sickle Cell Disease (SCD) is a common lifelong genetic disorder of red blood cells, which causes abnormal hemoglobin shape often resulting in pain crises and other serious health complications (Ware, et al., 2017). SCD disproportionally affects people of African descent, and several recent surveys have shown that patients with SCD experience discrimination in healthcare settings (Nelson and Hackman, 2013; Haywood, et al., 2014; Kanter, 2020; Oyedeji and Strouse, 2020). In pediatrics, parents of patients with SCD report higher levels of race-related discrimination in healthcare settings compared to families with other chronic illnesses, as well as decreased satisfaction in several areas of their care (Brousseau, 2009; Oyedeji, 2020; Kanter, et al., 2020). This qualitative project aimed to explore further specific, actionable areas of dissatisfaction and any areas of increased satisfaction among pediatric patients with SCD and their families.
Methods: Semi-structured interviews were conducted with pediatric patients with SCD and/or their guardians at one academic institution. Any patient with SCD over the age of eight was eligible to participate in an interview, and parents of a child with SCD of any age were eligible to participate, as well. Interviews were audio-recorded and took place in person in clinic. Recordings were then transcribed verbatim. The interviews were qualitatively coded using standard multi-level semantic analysis, working directly from the transcriptions and audio-recordings. Seven (41%) interviews were independently double-coded, and discrepancies were resolved by consensus. Final codes were analyzed, and major themes were identified.
Results: Eighteen pediatric patients with SCD and/or their families were asked to participate in the study, and seventeen (94%) agreed. There were twenty-six total participants. Ten family interviews were conducted, and another seven were conducted with parents only because the patients were younger than eight years old. Fifteen families identified as African American, one family identified as Hispanic, and one family identified as African. Patients and their families described five main areas leading to dissatisfaction in the healthcare setting: (1) Long wait times; (2) Neglect for SCD protocols within emergency departments; (3) Biases against patients with sickle cell disease; (4) Frustration with procedures, specifically with blood draws; (5) Lack of empathy and compassionate listening among healthcare providers. Positive experiences were almost all due to aspects of strong patient-provider relationships. Outside of the healthcare setting, patients and their families emphasized the need for improved education and awareness of SCD within the community.
Conclusion: While this qualitative study explored perspectives from only a limited number of pediatric families, these conversations provided insight into specific areas of dissatisfaction among patients with SCD. This research provides actionable items that healthcare providers can apply to help improve the healthcare experiences and the everyday lives of children with SCD. Additional efforts and resources should be directed toward addressing social determinants of health and systemic racism to future improve healthcare experiences of patients with SCD.

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