Parent Perspectives on Documentation and Sharing of Health-related Social Needs Data

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Parents of pediatric patients are key stakeholders in the design and implementation of health-related social needs (HRSN) screening programs. Yet, there is little research exploring their perspectives on the documentation and sharing of HRSN data. We aimed to examine parents' preferences regarding how HRSN data are documented and shared. We conducted semi-structured interviews with parents of hospitalized children participating in an HRSN screening program at a quaternary care children's hospital. Interviews were coded using an inductive and deductive approach to identify emergent themes. The 20 interviewed parents were uniformly female with 55% identifying as Black or African American and 20% identifying as Hispanic or Latino. Parents expressed comfort with electronic health record documentation of HRSN data and the use of International Classification of Diseases, 10th Revision Z codes as long as this information was used to provide families with meaningful support. Most parents viewed social workers and medical teams as the most appropriate recipients of HRSN data. Few parents felt comfortable with HRSN data being shared with payors. Parents desired transparency around HRSN data sharing. Many expressed concerns that documentation and sharing of HRSN data could lead to unwanted or unsafe disclosures or result in child welfare referrals. Parents expressed comfort with HRSN documentation and sharing with health care providers, but requested that providers be transparent and respect parental preferences regarding data sharing to mitigate potential harms. When implementing HRSN support programs, health systems and payors should prioritize transparency around documentation and data sharing with families.

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