Children's Hospital of Philadelphia PolicyLab

Barriers and Facilitators to Caregiver Comfort With Health-related Social Needs Data Collection in the Pediatric Clinical Setting

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Objective: To identify barriers and facilitators to family-level comfort with health-related social needs (HRSN) data collection and documentation in the pediatric clinical setting.

Study setting and design: This qualitative study was nested within a pragmatic randomized controlled trial on social care integration in the pediatric clinical setting. We used a hybrid random-purposive strategy to sample 60 caregivers of pediatric patients ages 0-25 presenting at two primary care clinics and one emergency department affiliated with a large pediatric healthcare system between September 2022 and 2023. We developed an interview guide and codebook to explore caregiver experiences with and perceptions of HRSN data collection and documentation.

Data sources and analytic sample: We conducted semi-structured telephone interviews in English and Spanish with 60 caregivers. Interviews were conducted until thematic saturation was achieved and were transcribed verbatim. We used thematic analysis with constant comparison to code interviews and identify emerging themes.

Principal findings: Our analysis yielded several barriers to caregiver comfort with HRSN data collection and documentation: (1) stigmatization by providers and medical staff and risk of child protective services involvement, (2) providers presuming connections between documented HRSN and medical complaints, (3) permanency of documented HRSN, (4) visibility of HRSN data by pediatric patients and caregiver proxies, and (5) fear that documented HRSN could negatively impact future insurance cost and coverage. We identified four facilitators to caregiver comfort: (1) clear communication regarding the purpose of HRSN data collection and use, (2) respect for caregiver autonomy, for example, by providing the option to decline participation, (3) training of data collection personnel to ensure privacy and compassionate care, and (4) consideration of timing within the medical visit, delaying assessment until medical concerns are addressed.

Conclusions: Caregiver-identified barriers and facilitators should be considered in clinically based HRSN data collection efforts to ensure that these programs are equitable and family-centered.

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