

NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

Submission Id: 6714

Title

“We feel alone and not listened to”: Somali, Hmong and Latin American Parents’ Perspectives on Pediatric Serious Illness

Priority 1 (Research Category)

Child and adolescent health

Presenters

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Abstract

Context: The experience of ethnically diverse parents of children with serious illness in the US healthcare system has not been well studied. Listening to families from these communities about their experiences could identify modifiable barriers to quality pediatric serious illness care and facilitate the development of potential improvements. Objective: Identify parents’ perspectives about good healthcare, poor healthcare and needed improvements in healthcare for children’s serious illness from Somali, Hmong, and Latin American communities. Study Methods and Analysis: Qualitative community-based participatory action research (CBPAR) study with focus groups and individual interviews. Common themes were identified inductively through immersion-crystallization, and a participatory analysis process that included Somali, Hmong, and Latin Americans as research team and community advisory board members. Setting: Minneapolis-St Paul metropolitan area. Participants: Twenty-six parent participants (eight Somali, ten Hmong, and eight Latin American) of children with serious illness were recruited through local clinics and hospitals. Intervention: NA. Outcome measures: NA. Results: Parents desired two-way trusting and respectful relationships with medical staff. Three themes supported this trust, based on parents’ experiences with challenging and supportive healthcare: 1) Informed understanding allows parents to understand and prepare for their child’s medical care; 2) Compassionate interactions with staff allow parents to feel their children are cared for; 3) Respected parental advocacy allows parents to feel their wisdom is heard. Effective communication is one key to improving understanding, expressing compassion, and partnering with parents, including quality medical interpretation for low-English proficient parents. Conclusions: Parents of children with serious illness from Somali, Hmong, and Latin American communities shared a desire for authentic relationships with

staff and improved health care processes. Processes that enhance communication, support, and connection, including individual and system-level interventions driven by community voices, hold the potential for reducing health disparities in pediatric serious illness.

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