

# The Process of Safety Reporting by Parents of Hospitalized **Children with Medical Complexity**

# BACKGROUND

- Parents of children with medical complexity (CMC) have valid safety concerns. However, little is known about parents' experiences with reporting during hospitalization and there is no system to capture their safety concerns.
- Objective: to describe the process of family safety concern reporting by parents of CMC.

# METHODS

# Design, Subjects, and Setting

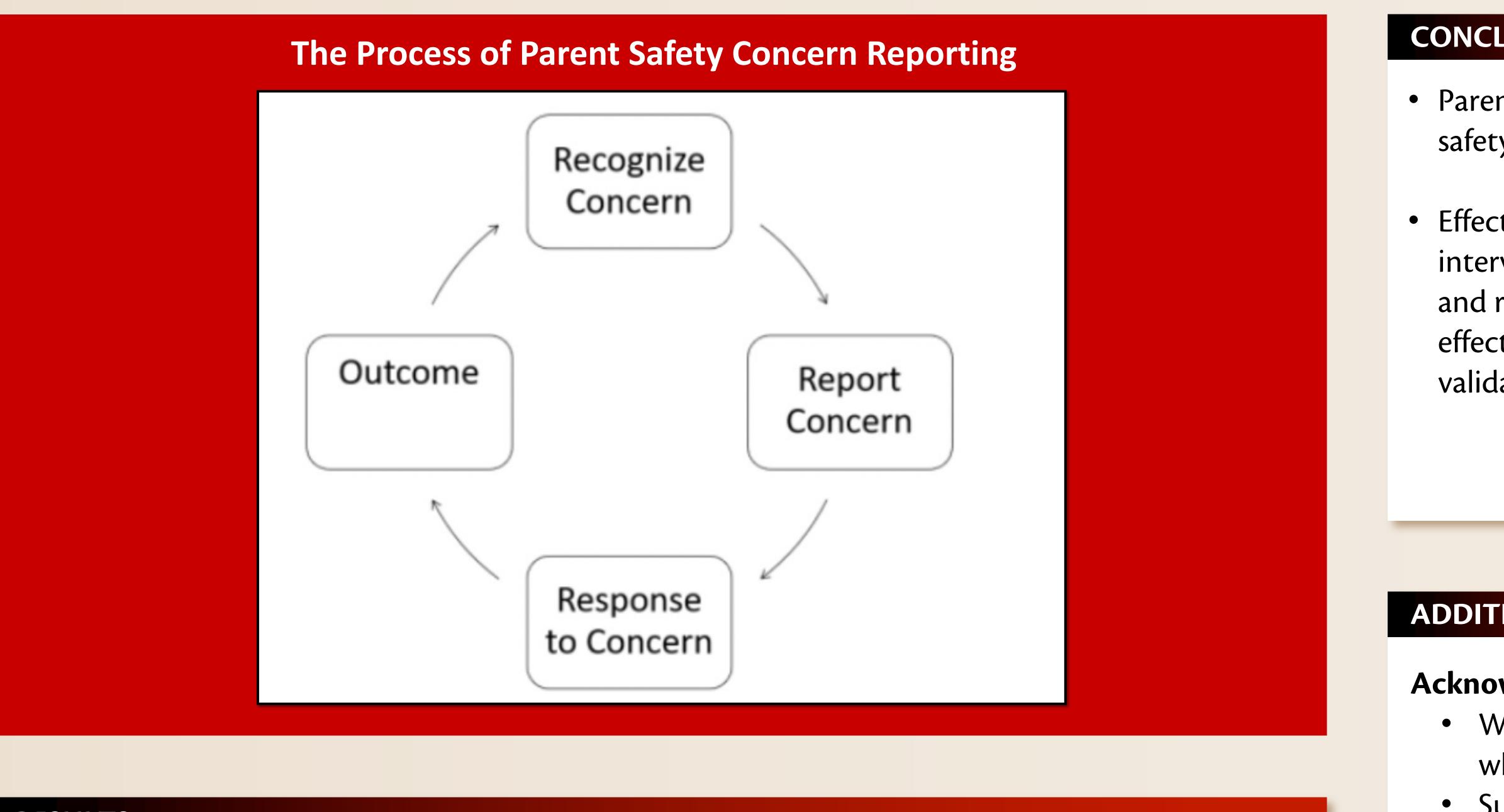
- Secondary analysis of qualitative data from a larger, mixed methods study (Family Activation and Communication about Errors and Safety: 'FACES').
- Semi-structured interviews with 34 English- and Spanish-speaking parents of CMC.
- December 2018 to July 2021.
- Two tertiary care children's hospitals.

# **Data Collection and Analysis**

- Three researchers inductively and deductively coded the transcripts using an iteratively refined codebook with validation by a fourth researcher.
- A conceptual model of family safety reporting was created.

Madeline Kieren, BA<sup>1</sup>, Michelle Kelly, MD, PhD<sup>1</sup>, Tessa Chen<sup>1</sup>, Miguel Garcia<sup>1</sup>, Tiffany Ngo, MA<sup>2</sup>, Alisa Khan, MD, MPH<sup>2</sup>

<sup>1</sup>University of Wisconsin – Madison School of Medicine and Public Health, Department of Pediatrics <sup>2</sup>Division of General Pediatrics, Department of Medicine, Boston Children's Hospital



### RESULTS

Four steps emerged illustrating the process of safety reporting (Figure) Parent recognizing concern: Parents must first recognize that a safety concern occurred, fallibility exists in the system, and they have the expertise to report.

"The doctors] were right on it, but the initial [IV] infiltration, I think I saw first."

• **Parent reporting concern:** Parents described variable timing and mode of reporting but say it is most commonly verbally and in real-time.

"I told [the nurse] in the moment, I didn't let time pass by."

Staff/hospital response to concern: The response from staff to parent safety concerns varied in whether the concern was acknowledged and addressed.

"I was even told point blank, 'You're coming to the best hospital in [location] for a reason. Let us do our job. We know what we're doing.""

• Parent feelings of validation: There was a spectrum in how parents felt in the aftermath of reporting, from feeling overlooked to feeling heard or seen.

"[I felt] angry, emotional, helpless. I'm not usually one to feel helpless...And there was one particular attending in the complex care team who was constantly discounting or dismissing my feedback."

# Acknowledgements

# Next Steps

# **Contact Information**



# UwHealth

**American Family** Children's Hospital



**Department of Pediatrics** JNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE AND PUBLIC HEALTH

# CONCLUSIONS

• Parents identify multiple steps in reporting safety concerns in the inpatient setting.

 Effective family safety reporting interventions must help parents recognize and report concerns and help staff effectively respond to, acknowledge, and validate parent concerns.

# **ADDITIONAL KEY INFORMATION**

• We would like to thank all the parents who participated in this study. • Support was provided by the Agency for Healthcare Research & Quality K08HS025781 grant (PI Khan) and an American Pediatric Association Young Investigator Award (PI Khan).

• R01 to refine and test a parent safety reporting tool.

 Madeline Kieren, BA mkieren@wisc.edu • Michelle Kelly, MD, PhD michelle.kelly@wisc.edu Alisa Khan, MD, MPH alisa.khan@childrens.harvard.edu