BACKGROUND: In the United States, many states do not offer long-term care for pediatric tracheostomy and ventilator-dependent patients. This results in eventual discharge home for large numbers of tracheostomy-dependent patients regardless of the health literacy, social situation, or resources available to families. There has been relatively little study of appropriate quality and safety standards in the outpatient setting.

OBJECTIVES:

- To understand barriers to the creation of a culture of safety in pediatric tracheostomy home care
- To identify sources of excessive variation in home tracheostomy care

METHODS: Semi-structured interviews with home health organizations, hospital administrators, state-level program administrators, and patient families were conducted to understand barriers to creation of a culture of safety in home care. Qualitative thematic analysis was used to interpret interview data.

RESULTS:

- 18 interviews were conducted with stakeholders across the spectrum of tracheostomy home care for pediatric patients. Thematic analysis yielded 5 major classes of barriers facing all stakeholders. Home health agencies identified consistent concerns and reported negative impact from competition within the industry. Family caregivers reported inconsistent support and frequent conflict with agencies and programs designed to support them. Stakeholders face conflicting priorities and pressures when attempting to resolve common challenges.

CONCLUSIONS: Home care for children with tracheostomies is poorly standardized, subject to multiple barriers, and often falls short of providing high-quality care. Outpatient safety and quality initiatives for tracheostomy patients are needed, and should incorporate priorities of all involved stakeholders.

FUTURE DIRECTIONS:

- Standardization of basic outpatient outcomes reporting for pediatric tracheostomy patients
- Partnerships between health systems and home health agencies for care continuity